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

NHS Greater Glasgow and Clyde

Glasgow Haemophilia Comprehensive Care Centre

Glasgow Royal Infirmary – Adult service

Visit Date: 16th May 2019

Report Date: September 2019

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Introduction

This report presents the findings of the peer review of services for adults with Inherited and Acquired Haemophilia and other Bleeding Disorders at Glasgow Haemophilia Comprehensive Care Centre at the Glasgow Royal Infirmary, which took place on 16th May 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 Doctor's 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:

- Glasgow Royal Infirmary
- NHS Greater Glasgow and Clyde

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 Glasgow Royal Infirmary Comprehensive Care Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are grateful too to the patients 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 Quality Review Service

QRS 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 QRS is available at www.qualityreviewservicewm.nhs.uk

Glasgow Haemophilia Comprehensive Care Centre – Adult Service

NHS Greater Glasgow & Clyde (NHS GGC) was a single Health Board with four acute hospitals (Glasgow Royal Infirmary (GRI), Queen Elizabeth University Hospital (QEUH), Royal Alexandra Hospital (RAH) and the Inverclyde Royal Hospital (IRH)) and three ambulatory care hospitals caring for a total population of approximately 1.2 million. NHS GGC hosted both adult and paediatric haemophilia services, delivered at Glasgow Royal Infirmary (GRI) and the Royal Hospital for Children (RHC, based at the QEUH site) respectively. The adult and paediatric haemophilia services were registered as a single Haemophilia Comprehensive Care Centre and delivered care for patients in NHS GGC and the surrounding Health Boards (Lanarkshire, Dumfries & Galloway, Ayrshire & Arran, the Western Isles and parts of Forth Valley and Highlands) with a total catchment population of approximately 2.6 million.

The RHC opened in June 2015 and was the largest paediatric teaching hospital in Scotland. It provided secondary care for children in Greater Glasgow and Clyde (GGC) and tertiary paediatric services for the west of Scotland. Several nationally designated services were delivered by the hospital and all paediatric medical and surgical subspecialties were represented on site, including paediatric intensive care.

Managerially, the paediatric services came under the Women & Children's Directorate, while the adult services were under the management of the Regional Services Directorate. Day-to-day clinical services were provided by dedicated medical and nursing staff separately at the RHC for children and GRI for adults. Out-of-hours medical cover was also provided by separate adult and paediatric teams. However, the adult and paediatric haemophilia teams communicated regularly, met quarterly and generally operated to common policies and protocols, many of which had been developed and agreed through the Scottish Inherited Bleeding Disorders Network (SIBDN).

Haemophilia services in Scotland were not nationally commissioned, although provision of coagulation factor concentrates was nationally commissioned through a risk-sharing agreement facilitated by the National Services Division (NSD). The NSD held Service Level Agreements with GRI (for NHS GGC and the west of Scotland) and Royal Infirmary Edinburgh (for NHS Lothian and the east of Scotland). All coagulation factor products for NHS GGC and the west of Scotland were purchased through GRI (or via home delivery which accounted for approximately 88% of product used) and were distributed to the RHC (or an outlying Health Board if required).

At the time of the visit the number of adults registered at the Comprehensive Care Centre was as follows:

Condition	**No. patients**	**Number**	**No. patients who had an annual review in last year**	**Number**	**No. inpatient admissions in last year**	**Number**
Haemophilia A	Severe	57	Severe	54	Severe	7
+ Carriers with levels <45%	Moderate	15	Moderate	10	Moderate	3
	Mild	150	Mild	86	Mild	8
Haemophilia B	Severe	13	Severe	12	Severe	0
+ Carriers with levels <45%	Moderate	17	Moderate	8	Moderate	1
	Mild	59	Mild	21	Mild	0
Von Willebrand	Severe	35	Severe	24	Severe	1
	Mild	568	Mild	160	Mild	3
Other	Severe	40	Severe	27	Severe	1
	Mild	415	Mild	325	Mild	11

Please note the definitions used to categorise as mild/moderate/severe in this table are as stated below:

- Haemophilia A & B (including carriers): <1% = severe; 1-5% = moderate; >5-45% = mild. Therefore, any carriers >45% will not be included in the table.
- Von Willebrand Disease: RCo (or CBA) <10% = severe; all others mild
- Platelet disorders: all cases of BS or GT = severe; all other platelet disorders = mild
- Unexplained bleeders = mild
- HypoFg: <0.5g/L = severe; all others and all DysFg = mild
- Other Factor deficiencies: level <10% = severe; all others = mild; combined V&VIII = severe
- Acquired VWS: if RCo <10% = severe
- Acquired Haemophilia A: all severe assuming inhibitor positive (even if FVIII is not <1%)

Emergency Care

During routine hours (Monday to Friday 8.30am to 4.30pm) patients were asked to phone the haemophilia unit for initial advice (e.g. to self-treat), to attend the unit or to go directly to the Emergency Department (ED) or Acute Assessment Unit (AAU) to determine the most appropriate pathway for treatment. If a patient was directed to the ED or AAU, haemophilia unit staff would inform the ED (or AAU) of the patient's impending arrival and would give instructions on the initial haemostatic measures that were likely to be required. Out of hours, patients were directed to the on-call the haematologist, via the switchboard at GRI, who would give advice as above and inform and advise the ED (or AAU) if a patient was to attend there. ED staff at GRI also had access to relevant haemostasis guidelines (in particular, 'Inherited Bleeding Disorder Patients presenting at GRI ED with bleeding or trauma') and could access brief bleeding disorder details from the patient's Electronic Patient Record on the Clinical Portal. A similar document had been developed for EDs at other hospitals in GGC and the West of Scotland, to assist with the emergency management of patients with inherited bleeding disorders presenting somewhere other than the GRI.

Ward Care

There was no dedicated haematology or 'medical' ward for haemophilia patients at GRI. Elective admissions for surgery were to the relevant surgical subspecialty ward. Emergency surgical admissions were to the acute surgery admissions ward. Virtually all non-surgical admissions were emergencies, and patients would be admitted to the acute medical admission wards (Wards 50-53). Once stabilised, medical admission patients would be transferred to the relevant specialty ward within GRI. Depending on the reason for admission, almost all patients would be reviewed by a consultant haematologist within the first 24 hours of admission with ongoing senior haematology medical or nursing review on a daily basis.

Day Care

This was delivered through the dedicated Haemophilia & Thrombosis Centre at GRI (Monday to Friday 8.30am to 4.30pm), which was staffed by haemophilia specialist nursing and medical staff. All haemophilia outpatient clinic reviews and day case activities were provided at this unit. Patients with other non-malignant haematology disorders (e.g. haemoglobinopathy disorders, ITP etc.) could also attend this unit for outpatient review or day case procedures. The Centre included four consulting rooms, a treatment area for three to four patients, and a waiting room, as well as staff offices and a small seminar room.

Outpatient Care

Adult bleeding disorder outpatient care was delivered via the Haemophilia & Thrombosis Centre at GRI (see above). There was a weekly haemophilia clinic every Tuesday morning followed by an MDT meeting to discuss

patients seen in the preceding clinic, upcoming patients for surgery and any ongoing inpatients or complex outpatients. There was also a monthly haemophilia carrier clinic. Urgent outpatient reviews that could not wait until the next available Tuesday clinic appointment, could be organised at any time during normal working hours. The senior Haemophilia charge nurse also ran a monthly telephone clinic for some of patients with milder bleeding disorders.

In addition, the senior Haemophilia charge nurse provided outreach clinics in two of the distant Health Board areas (Dumfries & Galloway, and Ayrshire & Arran). These were held every two to three months and were also attended by a local consultant haematologist with an interest in haemostasis.

Community-based Care

The demand / requirement for community-based care for the adult population with bleeding disorders was very small. However, with the increasing age of some patients, and the distances required to travel to GRI, the team had established small outreach clinics (as above) and also visited patients in the community occasionally (as needed on an individual basis).

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Review Visit Findings

Achievements

The team was providing good quality patient and family-focused services. All staff groups were hardworking and dedicated including the medical staff, the operational manager who undertook a variety of extended roles, and the psychologist who was making a big difference for patients within the limited time available and was using innovative ways of connecting with patients including by offering 'skype' counselling. The nurses worked flexibly (over and above their contracted hours) sometimes coming into the Centre at weekends to see patients and also visiting them at home or when they were inpatients at other hospitals. The laboratory team were continuing to offer the full range of routine and specialist investigations, whilst also spending time evaluating some new analysers.

Patients were overwhelmingly positive about the care that they received, and they appreciated being made to feel a part of the team, which was described as being 'like an extended family'. Patients were invited to mentor each other, and they appreciated being invited to social events hosted by the team.

There was an active research programme with patients from the Centre being involved in several high-level national trials.

A Scotland-wide achievement was the SIBDN, which has been established in 2016, to facilitate clinical and other improvements for individuals with inherited bleeding disorders. Three active work-streams were: Stakeholder Engagement and Communication; Best Practice, Policies and Protocols; and Quality Improvement, Audit and Data. The network had successfully published some national guidelines, produced a comprehensive patient information booklet, and undertaken Scotland-wide auditing of data against a set of Key Performance Indicators. It held regular educational events. Commissioners regularly attended the network meetings, and there was a full annual report and work-plan. Members of the Glasgow team had made significant contributions to the activity of the SIBDN.

Immediate Risks[1]

Two immediate risks were identified at the time of the visit, as follows:

1. **Emergency Department guideline**

   In the 'short guide' for use in the ED at the Glasgow Royal Infirmary and in the guidelines intended for managing patients at Emergency Departments in other hospitals in the West of Scotland, the dose of DDAVP (for use in bleeding or trauma, in patients with mild haemophilia A), was incorrectly given at 15 ug/kg rather than the correct dose of 0.3 ug/kg. **I**f administered, this large dose would lead to serious clinical consequences**.**

2. **Resuscitation Training for clinical staff at the Centre**

   At the time of the visit none of the senior doctors and only one of the specialist nurses in the haemophilia team had up to date Basic Life Support training. This was considered a risk as patients in the Centre were receiving blood transfusion, and factor administration which could give rise to anaphylaxis. It is essential

[1] **Centre response to Immediate Risks** – **(1)** ***Emergency Department (ED) Guidance*** **-** The typographical error in the two documents has now been corrected. These were new documents and no hard copies were in general circulation. The incorrect electronic version on the ED intranet page has been removed and replaced with the corrected version. (***2) Resuscitation Training for clinical staff at the Centre*** **-** A dedicated Basic Life Support training session for the whole Haemophilia clinical team was held on the afternoon of the 28th May 2019.
QRS Response – we have considered your response and confirm that the actions, as described, will address the immediate risk.

that at all times, when patients are receiving treatment, at least some staff working in the Centre have up to date training in at least Basic Life Support.

Good Practice

1. Patients felt confident in the care they received when presenting to the ED out of hours. ED staff were well trained about acute presentations in patients with bleeding disorders, and haemophilia had been the subject of a 'themed week' for training in the ED.
2. There was a nurse-led telephone clinic, mostly for patients with minor bleeding disorders, which was especially valuable for those living long distances from the Centre.
3. A written checklist for use during clinic consultations ensured consistent and thorough assessment.
4. The lead nurse offered specialist input at outreach clinics, working alongside the local haematologist, at two different sites for a total of eight sessions per year, despite travelling distances of two hours or more.
5. There was a monthly clinic for meeting and counselling carrier women, run by one of the co-director consultants and the lead nurse. Carrier status was confirmed by genetic testing.
6. Transition practice was good. Transfer of care from paediatric to adult services took place after the young person left school at between 16 and 18 years of age. A consultant and nurse went across to the Royal Children's Hospital (which was seven miles away) to join the paediatric team seeing the young person and their family. The young person was also offered an introductory visit and a tour of the adult centre before their care was formally taken over.
7. The management of patients with blood-borne virus infections was excellent, with outstanding outcomes and survival rates.
8. Radioactive synovectomy[2] was offered on site.
9. Pharmacokinetic information for patients receiving extended half-life products was imaginatively used, with patients understanding their own 'factor level vs time after injection' graphs and using them to guide what factor dose to self-administer in case of trauma or bleed, according to the time since their last prophylactic dose.
10. Operational and clinical managers were receptive and supportive.
11. There were many excellent documents supporting the service. These included: a plentiful supply of patient information, which was well displayed around the Centre; policies and guidelines including a comprehensive operational policy that contained guidance as to which patients would be suitable for telephone clinics and a checklist for use during telephone consultations; guidelines on antenatal care delivery and care of the neonate; surgical guidelines and a leaflet describing the genetic counselling service.
12. The IT system supported the service well, with an immediate alert appearing on screen as soon as a patient's record was opened, and the facility for remote access for on-call staff to view letters and results for patients at GRI and other linked hospitals using the same system. Staff could also enter comments remotely to record the advice they gave.
13. There were designated parking spaces for Centre users which were close to the Centre reducing the walking distance for patients.

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

Concerns

1. **Staffing**

    a. **Physiotherapy:** There were two named therapists, but they had less than one session per week between them dedicated to the bleeding disorders service. They did not attend the haemophilia clinic MDT meetings, many patients had not recently had a formally assessed joint score and did not work as integrated members of the team. The service was reactive, and the therapists were not usually available to assess and help manage acute joint bleeds. Many patients had not recently had a formally assessed joint score.

    b. **Psychology**: The clinical psychologist was a valued team member but worked at this Centre for only three days per month, as this was a network post that was shared with the Edinburgh CCC. The psychologist could not therefore attend joint clinics or MDT meetings. Funding for the post was temporary continuing only to the end of the 2019/20 financial year and at the time of the visit there was no plan in place to extend the funding.

    c. **Effective MDT working:** The limited time allocated to the service for these team members meant that the Centre team could not work in the expected integrated multi-disciplinary manner.

    d. **Data management**: Staff at the Centre were additionally managing some aspects of the SIBDN. The review team noted that the needs and prioritisation of local, as opposed to, national requirements should be reviewed.

2. **Fridges**

    Two fridges in the department (one holding factor stock for patients to collect and use at home, and the other containing emergency factor stock) were unlocked and were accessible to anyone entering the Centre.

Further Consideration

1. The review team heard that the Centre was likely to be moved from its current location (conveniently near to a main hospital entrance and on the ground floor) to create accommodation for a hospital discharge facility. The proposed new site for the Centre, of approximately the same size, was considerably more difficult to access, being further from an external hospital entrance, and on a different level. The process was being managed transparently, and active ongoing discussions included a patient engagement group. However, ensuring appropriate access to the new clinical area for patients with limited mobility remained a challenge, and all possible solutions needed to be considered.

2. Rheumatology support for the service was unusually strong, with a senior rheumatologist undertaking much of the routine joint assessment and management. When this lead consultant retires, the team will need to consider how they can continue to provide this level of clinical service.

3. The lead nurse had undertaken the 'Contemporary Care of People with Bleeding Disorders' course, and one other nurse was booked to attend later in the year. All the nurse specialists should be supported to undertake this training.

4. Audit activity was evident, including a useful telephone message response audit, and there was a clear audit pro-forma, but there was no systematic programme of audits in place or planned, to cover adherence to clinical guidelines, or clinic reviews including joint scores (QS HP-702). Performance against some national Key Performance Indicators provided useful comparator audit data, but there were no expected or achievable percentage compliances or 'red / amber / green' thresholds to allow the Centre to monitor progress.

5. There was a 1:4 consultant on-call out of hours rota between the two co-directors, a third consultant with bleeding disorder training and expertise, and a fourth consultant haemato-oncologist. When the latter was

on call, the associate specialist took bleeding disorder service calls, backed up by the two co-directors in an informal 'second on' capacity. Reviewers considered that this could be formalised.

6. It was not usual practice to copy clinic letters to patients, although this might be considered as a way of ensuring patients have a reminder and a record of what was discussed and agreed during consultations.

7. The contact number for the paediatric day care area and advanced nurse practitioner in the operational policy was not correct, as the facility on the Children's Hospital site had temporarily relocated from its usual ward area.

8. Document control was not consistent. Many but not all policies and guidelines indicated authorship and dates of issue / for review. For example, the guideline 'Monitoring and management of haemophilic arthropathy' lacked these details, and other guidelines, including those for managing post-operative pain, were beyond their review date.

9. The SIBDN had a named lead Consultant, but no named lead nurse, physiotherapist or psychologist. Consideration might be given to appointing to these lead roles to ensure balance in discussions and direction and to promote the involvement and progression of senior professionals in these fields. Other professional groups could also be represented at the two-monthly haemophilia directors' teleconferences.

10. The SIBDN had recently produced a draft handbook, which was comprehensive. A couple of small errors of content were identified. These were notified to the operational manager who agreed to discuss them with the authors of the document.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Beverley Barnett	Senior Biomedical Scientist	Hull and East Yorkshire Hospitals NHS Trust
Andy Cowe	Patient representative	
Dr John Hanley	Consultant Haematologist	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
David Hopper	Clinical Specialist Physiotherapist Haemophilia	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
Helen Hupston	Clinical Nurse Specialist	University Hospitals Birmingham NHS Foundation Trust

QRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	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 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

	Number of Applicable QS	Number of QS Met	% met
Comprehensive Care	37	28	76%
Network	8	4	50%
Commissioning	3	3	100%
Total	48	35	73%

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

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

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

Ref	Standard	Met?	Comments
HP-103	**Plan of Care** Each patient and, where appropriate, their carer should discuss and agree their Plan of Care, and should be offered a written record covering at least: a. Agreed goals, including life-style goals b. Self-management c. Planned assessments, therapeutic and/or rehabilitation interventions d. Early warning signs of problems, including acute exacerbations, and what to do if these occur e. Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) f. Planned review date and how to access a review more quickly, if necessary g. Who to contact with queries or for advice The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.	Y	
HP-104	**Review of Plan of Care** A formal review of the patient's Plan of Care should take place at least six monthly for patients with severe or moderate haemophilia and at least annually for other patients. This review should involve the patient, where appropriate their carer, and appropriate members of the multi-disciplinary team. Haemtrack results should be reviewed (if applicable) and the outcome of the review should be communicated in writing to the patient and their GP.	Y	See Further Consideration section of main report regarding copying of clinic letters to patients.
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	Y	
HP-198	**Carers' Needs** Carers should be offered information on: a. How to access an assessment of their own needs b. What to do in an emergency c. Services available to provide support	Y	
HP-199	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive b. Mechanisms for involving patients and carers in decisions about the organisation of the service c. Examples of changes made as a result of feedback and involvement of patients and carers	Y	

Ref	Standard	Met?	Comments
HP-201	**Lead Consultant and Lead Nurse** A nominated lead consultant and lead nurse should have responsibility for staffing, training, guidelines and protocols, service organisation, governance and for liaison with other services. The lead consultant and lead nurse should be registered healthcare professionals with appropriate specialist competences and should undertake regular clinical work within the service and specific time allocated for their leadership role.	Y	
HP-202	**Staffing Levels and Skill Mix** Sufficient staff with appropriate competences should be available for out-patient, day unit and in-patient care and for support to urgent care services. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network. All staff should undertake regular Continuing Professional Development of relevance to their work in the inherited and acquired bleeding disorders services. Staff working with children and young people should have competences in caring for children as well as in the care of people with bleeding disorders. Cover for absences should be available. In HCCCs these staff should have sessional time allocated to their work with the IABD service. In HCs the arrangements for accessing staff who do not have sessional time allocated to the IABD service should be clearly defined. Staffing should include: a. Medical staff: i. Consultant specialising in the care of people with inherited and acquired bleeding disorders available during normal working hours ii. On-call consultant haematologist (24/7) iii. Arrangements for advice from a consultant specialising the care of people with inherited and acquired bleeding disorders (if not on call) b. Specialist nursing staff: i. Bleeding disorders specialist nurses (5/7) ii. Ward, out-patient and day unit staff with competences in the care of people with inherited and acquired bleeding disorders. c. Clinical specialist physiotherapist d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303) e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist f. Specialist senior social worker g. Data manager	N	See 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.	Y	
HP-204	**Competences – All Health and Social Care Professionals** All health and social care professionals working in the service should have competences appropriate to their role in: a. Safeguarding children and/or vulnerable adults b. Recognising and meeting the needs of vulnerable children and/or adults c. Dealing with challenging behaviour, violence and aggression d. Mental Capacity Act and Deprivation of Liberty Safeguards e. Resuscitation	N	See Immediate Risks section of main report.
HP-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be available.	Y	However, see Concerns section of main report regarding staffing and the possible overlap between Centre and Network responsibilities.
HP-301	**Support Services** Timely access to the following support services should be available: a. Play support (children's services only) including: i. Play and distraction during any painful or invasive procedures ii. Play support to enable the child's development and well-being b. Pharmacy c. Dietetics d. Occupational Therapy e. Orthotics	Y	
HP-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department should have competences in urgent care of people with inherited and acquired bleeding disorders including awareness of: a. Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) b. Who to contact for advice	Y	

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 the continued provision of the existing laboratory services (routine and specialist) whilst new analysers were being validated.
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.	N	See Concerns section of main report regarding fridges.
HP-499	**IT System** IT systems should be in use for: b. Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree c. Patient administration, clinical records and outcome information d. Data to support service improvement, audit and revalidation e. Alerting the specialist team when patients attend the Emergency Department	Y	See Good Practice section of main report regarding remote access and alerts.
HP-501	**Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders** Guidelines on diagnosis should be in use covering at least a. Haemophilia A b. Haemophilia B c. Von Willebrand Disease d. Acquired haemophilia e. Inherited platelet disorders f. Other less common and rare bleeding disorders	Y	

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

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

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

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	N	See Concerns section of main report regarding physiotherapy provision.
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	The review team 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 evidence of a comprehensive range of completed audits. However, there was no forward audit programme, and the existing programme did not cover all elements of this Quality Standard.
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	Although many documents had good version control, some did not.

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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	Reviewers agreed with the Centre's self-assessment. There were no named leads for any professions other than the lead clinician.
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	There were some excellent network guidelines in place but they did not cover all those listed in Quality Standards HP-501, 502, 503, 504 and 505.
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	There was evidence of extensive audits being undertaken but they did not cover all the elements required for Quality Standard HP-702.
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	Reviewers agreed with the Centre's self-assessment; there was no network policy in place.

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	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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