



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

NHS Greater Glasgow and Clyde

Glasgow Haemophilia Comprehensive Care Centre

Royal Hospital for Children – Paediatric Service

Visit Date: 15th May 2019

Report Date: September 2019



8831





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Introduction

This report presents the findings of the peer review of services for children and young people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Glasgow Haemophilia Comprehensive Care Centre at the Royal Hospital for Children which took place on 15th 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 Doctors' Organisation (UKHCDO) Peer Review Working Group working with the Quality Review Service (QRS).

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

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

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

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

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

- Royal Hospital for Children
- 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 Royal Hospital for Children Haemophilia 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 and parents who took time to meet the review team.

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

About 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.qualityreview servicewm.nhs.uk

Glasgow Haemophilia Comprehensive Care Centre – Paediatric 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, 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 the 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 the 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 children registered at the Comprehensive Care Centre was as follows:

| Condition | | Number of patients | Number | Number of patients who had an annual review in last year | Number | Number of inpatient admissions in last year | Number |
|--|----------|--------------------|--------|--|--------|---|--------|
| Haemophilia A + Carriers with levels <45% | Children | Severe | 28 | Severe | 28 | Severe | 7 |
| | | Moderate | 7 | Moderate | 7 | Moderate | 1 |
| | | Mild | 45 | Mild | 31 | Mild | 0 |
| Haemophilia B + Carriers with levels <45% | Children | Severe | 4 | Severe | 4 | Severe | 1 |
| | | Moderate | 6 | Moderate | 5 | Moderate | 1 |
| | | Mild | 15 | Mild | 10 | Mild | 0 |
| Von Willebrand | Children | Severe | 10 | Severe | 10 | Severe | 0 |
| | | Mild | 91 | Mild | 59 | Mild | 2 |

| Condition | | Number of patients | Number | Number of patients who had an annual review in last year | Number | Number of inpatient admissions in last year | Number |
|-----------|----------|--------------------|--------|--|--------|---|--------|
| Other | Children | Severe | 1 | Severe | 1 | Severe | 0 |
| | | Mild | 98 | Mild | 61 | Mild | 0 |

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

Parents of children with inherited bleeding disorders were issued, at the time of diagnosis, with the contact number for the unit which could be used to access advice and treatment both during the day and out of hours.

During working hours, patients had direct access to the haemophilia unit, which was situated within the haematology oncology day ward (Ward 2B). For non-urgent conditions, parents were advised to contact the unit by telephone in advance. In more urgent circumstances they might be advised to phone for an ambulance, which would bring the child to the nearest Emergency Department (ED) (within GGC this would usually be at the RHC). Clinical alerts indicating a diagnosis of an inherited bleeding disorder were in place on the hospital electronic patient record system.

Out of hours, parents were advised to contact the haematology-oncology ward (Ward 2A) in advance. Staff would advise parents where to attend and would also alert the on-call haematology team and/or the ED to tell them that a patient was due to present. Dedicated haematology middle grade staff were on site until 10pm each day, after which the service was covered by the Hospital at Night (HaN) team. At weekends, and up until 10pm, patients could be reviewed on Ward 2A. After 10pm, they would present to the ED. Support and advice for haematology middle grade staff, ED staff and HaN was provided by a dedicated non-malignant consultant on-call rota.

Ward Care

Inpatient facilities were provided as part of a dedicated twenty-two bedded haematology oncology ward (Ward 2A). Children were accommodated in en-suite single rooms with pull-down parent beds.

Note: at the time of the visit, because of infection control issues, the ward facilities had been temporarily re-located to Ward 6A at QEUH.

Day Care

Patients were asked to attend the haemophilia unit situated within the haematology oncology day care ward (Ward 2B) for both scheduled and unscheduled reviews. Families had direct access to the unit during working hours.

Note: at the time of the visit, because of infection control issues, the ward facilities had been temporarily re-located to Ward 6A at QEUH. Some reviews were also taking place at RHC outpatients.

Outpatient Care

Outpatient services, included paediatric phlebotomy, were provided within the outpatient department at the RHC. There was a weekly haemostasis clinic and a monthly one-stop haemophilia clinic which included medical, nursing and physiotherapy reviews, for those patients with severe/moderate haemophilia.

Community-based Care

Home and school visits were provided by the haemophilia Advanced Nurse Practitioner. Home visits were used to establish and support prophylaxis and home treatment.

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Review Visit Findings

Achievements

This was a very strong service, delivered by dedicated and committed team members, all of whose positive contributions were noted. The strength of this service was especially impressive given the circumstances at the time of the review visit, which had required the Centre to relocate from its usual clinical area. Staff were continuing to deliver excellent care and were working well with colleagues in their temporary, shared, facility.

All of the patients and parents who met with the review team were extremely positive about the team, including some of its relatively new members. Patients felt very well cared for. They reported that the staff 'looked after the whole family'.

A Scotland-wide achievement was the SIBDN which had 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, including one detailing how to rotate short-dated stock to reduce waste. The network had produced a comprehensive patient information booklet, and had undertaken a Scotland-wide audit 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. The team at the RHC had made a significant contribution to this activity.

Good Practice

1. There was evidence of the efforts the team made to orientate and support new staff, with some excellent and detailed induction material.
2. Patient information was plentiful, with some especially useful documents, including information about the usual inpatient Ward 2A, a 'hospital passport', and a range of condition-specific information.
3. The diagnostic and clinical guidelines were all clear, well written, and adapted for local use.
4. There was a weekly educational session for Centre staff.
5. A training matrix included all the team members and identified the competences and training each member of staff needed for their role.
6. Children with severe disorders were systematically started early on prophylactic treatment, minimising from the start the incidence of joint bleeds and the risk of long-term joint damage.
7. 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 came across to the children's service from the adult service at the GRI (which was seven miles away) to join the paediatric team in meeting the young person and their family. The young person was then offered an introductory visit and a tour of the adult centre before their care was formally transferred.
8. There was a responsive specialist paediatric gynaecology clinic.
9. Clinical genetics offered an ongoing service once an index case child had been diagnosed and saw members of the extended family for testing and counselling.
10. The IT system supported the service well, with an immediate alert appearing on screen as soon as a patient's record was opened. In addition, the facility for remote access was in place for on-call staff to view letters and results for patients at the Glasgow Royal Infirmary and other linked hospitals using the same system. Staff could also enter comments remotely to record the advice they gave.

11. A clinic proforma ensured consistency of issues discussed and addressed at consultations. Information from this was fed into an audit form which was submitted into the annual Scotland-wide Key Performance Indicator matrix for assessing performance and benchmarking.
12. Families attending the Centre were provided with free car parking for four hours.
13. Patients and families travelling long distances to the Centre, for example from the Hebrides, could claim for reimbursement of travel expenses.

Immediate Risks: No immediate risks were identified at the time of the visit.

Concerns

1. Staffing

- a. **Nursing:** The two nurse specialists together constituted less than one Whole Time Equivalent (WTE), which was not sufficient for a service of this size. A business case had been submitted for an additional Band 6 nurse and if the business case was approved and a nurse was appointed this would bring the team to a more appropriate and sustainable level. Business cases had also been submitted for a number of other nursing posts within the Haematology-Oncology Directorate. A management plan to devolve the decisions to the clinical teams about which of these posts to support was considered unlikely to be productive.
- b. **Consultant staffing:** The Centre director had four sessions for work on bleeding disorders, and the other consultant with a special interest in bleeding disorders had two sessions. This equated to six sessions (0.6 WTE) which was not sufficient. There were complex out-of-hours rotas, covering different sub-specialties, and the two consultants with a special interest in bleeding disorders offered an informal 'second on' back-up for colleagues with less experience in this field. It would be beneficial for some of the other consultant medical staff to consider undertaking some related CPD, to work alongside the haemophilia consultants in clinic and to join MDT discussions to gain the necessary clinical experience. (See also Concern 2 'Out-of-hours telephone advice').
- c. **Psychology:** A clinical psychologist worked in this service one day per month. The contribution of this individual was highly valued, but the psychologist explained that she could only offer some initial intervention with subsequent signposting to other services. The importance of psychology support to children and families was not reflected in this allocation and did not enable fully integrated working with the wider MDT. The funding for this post was also temporary, lasting until the end of the financial year 2019/20 and at the time of the visit there was no plan in place to extend this.
- d. **Physiotherapy:** In the time allocated (two to three sessions per week), it was not possible for the physiotherapist to see all the severely and moderately affected children in clinic and to undertake their joint scores. Children were offered a separate appointment for this but often did not attend and the overall joint score completion rate was therefore only approximately 50%. Cover for the named physiotherapist was available, but the cover could be given by any of a number of colleagues, rather than a named deputy who could develop additional skills for working with this patient group.
- e. **Social Work:** There was no named social worker to whom the team could make referrals. Although the review team heard that it was not possible to have social workers employed directly by the hospital teams, it would be beneficial to identify one or two named social workers within the existing hospital service who could develop an interest in and understanding of the problems for children and families with bleeding disorders.
- f. **Clerical support:** Administrative and clerical time was insufficient for the requirements of the service. This resulted in nurses spending time making clinic appointments, generating travel letters, photocopying and scanning documents. This further detracted from their limited clinical time.

2. Out-of-hours telephone advice

Families expressed concern about the advice they received at times when non-specialist consultants were on call. In general, they were simply advised to bring the child to hospital, even with problems for which they knew the specialist consultants would have 'talked them through' home management. This was especially inconvenient for patients who lived long distances from the Centre.

Further Consideration

1. Although there was a great deal of patient information included in evidence, patients and families had not seen all of this, and the information could usefully be made more readily accessible to people visiting the Centre.¹
2. There was a written guideline for dental surgery, but no guideline for other types of surgery², and there was no written operational policy covering the elements of standard HP-601 (relating to a named consultant). The contents of the host team's response to self-assessment against this standard could form the basis of an operational policy.
3. Telephone contact numbers had not been updated in patient information about the Centre since the enforced move from the usual clinical area.
4. It was not usual practice to copy clinic letters to parents or carers, although this might be considered as a way of ensuring they have a reminder and a record of what was discussed and agreed during consultations.
5. As height and weight measurements were made in a different area of outpatients from where the child was subsequently seen and examined, parents sometimes had to undress and dress their children more than once when attending, and up to three times if they were additionally seeing the physiotherapist.
6. Research activity had been limited during the disruption engendered by the move to a different clinical area and it was hoped that this would resume once the service was re-established in its own clinical space.
7. A review of staffing needs to consider not just numbers of staff in each professional group, but also succession planning for nursing and medical staff.

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¹ The Centre had identified that ease of access to information had been more difficult recently because of the current ward decant. In the Ward 2B facility, information was readily available on display.

² The Centre has confirmed that, for surgery, the practice was to produce individual treatment protocols as required.

Network

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 areas. Other professional groups could also be represented at the two-monthly haemophilia directors' teleconferences.

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APPENDIX 1 Membership of Visiting Team

| Visiting Team | | |
|----------------|--|--|
| 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 |
| Dr Kate Khair | Clinical Academic | Great Ormond Street Hospital for Children 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 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 | 32 | 86% |
| Network | 8 | 4 | 50% |
| Commissioning | 3 | 3 | 100% |
| Total | 48 | 39 | 81% |

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Haemophilia Comprehensive Care Centres and Haemophilia Centres

| Ref | Standard | Met? | Comments |
|--------|--|------|----------|
| HP-101 | <p>Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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 | <p>Condition-Specific Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ul style="list-style-type: none"> 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 <p>Information should be available covering:</p> <ul style="list-style-type: none"> 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 | <p>However, some parents who spoke to the review team did not recognise some of the information, so consideration could be given to more proactive sharing of available information.</p> |

| Ref | Standard | Met? | Comments |
|--------|---|------|---|
| HP-103 | <p>Plan of Care</p> <p>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:</p> <ol style="list-style-type: none"> Agreed goals, including life-style goals Self-management Planned assessments, therapeutic and/or rehabilitation interventions Early warning signs of problems, including acute exacerbations, and what to do if these occur Agreed arrangements with school or other education provider and preparation for adult life (children and young people only) Planned review date and how to access a review more quickly, if necessary Who to contact with queries or for advice <p>The Plan of Care should be communicated to the patient's GP and to relevant other services involved in their care.</p> | Y | However, see Further Consideration section of the main report regarding copying of letters to families. |
| HP-104 | <p>Review of Plan of Care</p> <p>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.</p> | Y | |
| HP-105 | <p>Contact for Queries and Advice</p> <p>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.</p> | Y | |
| HP-106 | <p>Haemtrack (Patients on Home Therapy)</p> <p>All patients on home treatment should be encouraged to use electronic recording of their treatment through Haemtrack.</p> | Y | |

| Ref | Standard | Met? | Comments |
|--------|---|------|--|
| HP-194 | <p>Environment</p> <p>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.</p> <p>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.</p> | Y | Reviewers noted that there were temporary arrangements in place in terms of the ward location. |
| HP-195 | <p>Transition to Adult Services and Preparation for Adult Life</p> <p>Young people approaching the time when their care will transfer to adult services should be offered:</p> <ol style="list-style-type: none"> Information and support on taking responsibility for their own care The opportunity to discuss the transfer of care with paediatric and adult services A named coordinator for the transfer of care A preparation period prior to transfer Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards Advice for young people going away from home to study, including: <ol style="list-style-type: none"> registering with a GP how to access emergency and routine care how to access support from their Comprehensive Care Centre communication with their new GP | Y | |
| HP-198 | <p>Carers' Needs</p> <p>Carers should be offered information on:</p> <ol style="list-style-type: none"> How to access an assessment of their own needs What to do in an emergency Services available to provide support | Y | |
| HP-199 | <p>Involving Patients and Carers</p> <p>The service should have:</p> <ol style="list-style-type: none"> Mechanisms for receiving regular feedback from patients and carers about treatment and care they receive Mechanisms for involving patients and carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers | Y | |

| Ref | Standard | Met? | Comments |
|--------|--|------|--|
| HP-201 | <p>Lead Consultant and Lead Nurse</p> <p>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.</p> | Y | |
| HP-202 | <p>Staffing Levels and Skill Mix</p> <p>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:</p> <p>a. Medical staff:</p> <ol style="list-style-type: none"> 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) <p>b. Specialist nursing staff:</p> <ol style="list-style-type: none"> 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. <p>c. Clinical specialist physiotherapist</p> <p>d. Biomedical Scientist and Clinical Scientist (further detail on the requirements are included in HP-303)</p> <p>e. Clinical or counselling specialist psychologist or appropriately trained psychotherapist</p> <p>f. Specialist senior social worker</p> <p>g. Data manager</p> | N | See Concerns section of main report. Reviewers did not feel that the current doctor and nurse staffing levels were adequate for the size of the service. |

| Ref | Standard | Met? | Comments |
|--------|---|------|--|
| HP-203 | <p>Service Competences and Training Plan</p> <p>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.</p> | Y | |
| HP-204 | <p>Competences – All Health and Social Care Professionals</p> <p>All health and social care professionals working in the service should have competences appropriate to their role in:</p> <ol style="list-style-type: none"> Safeguarding children and/or vulnerable adults Recognising and meeting the needs of vulnerable children and/or adults Dealing with challenging behaviour, violence and aggression Mental Capacity Act and Deprivation of Liberty Safeguards Resuscitation | Y | |
| HP-299 | <p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be available.</p> | N | See the Concerns section of the main report. |
| HP-301 | <p>Support Services</p> <p>Timely access to the following support services should be available:</p> <ol style="list-style-type: none"> Play support (children's services only) including: <ol style="list-style-type: none"> Play and distraction during any painful or invasive procedures Play support to enable the child's development and well-being Pharmacy Dietetics Occupational Therapy Orthotics | Y | |
| HP-302 | <p>Emergency Department – Staff Competences</p> <p>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:</p> <ol style="list-style-type: none"> Guidelines on care of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) Who to contact for advice | Y | |

| Ref | Standard | Met? | Comments |
|--------|---|------|--|
| HP-303 | <p>Laboratory Service</p> <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> i. detection of causative mutations in patients with inherited bleeding disorders ii. carrier detection | Y | |
| HP-304 | <p>Specialist Services</p> <p>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:</p> <ul style="list-style-type: none"> 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 <p>Specialist services should have an appropriate level of specialist expertise in the care of people with inherited and acquired bleeding disorders.</p> | Y | See Good Practice section of the main report regarding genetics, the adolescent gynaecologist and two named dentists |

| Ref | Standard | Met? | Comments |
|--------|--|------|--|
| HP-402 | <p>Facilities and Equipment</p> <p>Facilities and equipment appropriate for the service provided should be available including:</p> <ol style="list-style-type: none"> Fridges Storage Clinical rooms for staff of all disciplines to see patients and carers Room for multi-disciplinary discussion Room for educational work with patients and carers Office space for staff Access to Haemtrack and the Haemophilia Centre Information System (HCIS) in all clinical areas <p>All equipment should be appropriately checked and maintained.</p> | Y | |
| HP-499 | <p>IT System</p> <p>IT systems should be in use for:</p> <ol style="list-style-type: none"> Storage, retrieval and transmission of patient information, including access to the latest vCJD status and family tree Patient administration, clinical records and outcome information Data to support service improvement, audit and revalidation Alerting the specialist team when patients attend the Emergency Department | Y | See Good Practice section of main report regarding clinical alerts |
| HP-501 | <p>Diagnosis Guidelines for Patients with Suspected Inherited and Acquired Bleeding Disorders</p> <p>Guidelines on diagnosis should be in use covering at least</p> <ol style="list-style-type: none"> Haemophilia A Haemophilia B Von Willebrand Disease Acquired haemophilia Inherited platelet disorders Other less common and rare bleeding disorders | Y | Clear and well documented local guidelines were in place |

| Ref | Standard | Met? | Comments |
|--------|---|------|--|
| HP-502 | <p>Guidelines: Concentrate Use and Monitoring</p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Concentrate therapy: <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> 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 | The Scottish guideline to reduce product waste was identified as good practice by reviewers. |
| HP-503 | <p>Clinical Guidelines</p> <p>The following clinical guidelines should be in use:</p> <ul style="list-style-type: none"> 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 | <p>Emergency Department Guidelines</p> <p>Guidelines on management of patients with inherited and acquired bleeding disorders in the Emergency Department should be in use.</p> | Y | |

| Ref | Standard | Met? | Comments |
|--------|--|------|---|
| HP-505 | <p>Guidelines on Care of Patients requiring Surgery</p> <p>Guidelines on the care of patients with inherited and acquired bleeding disorders who require surgery should be in use covering at least:</p> <ol style="list-style-type: none"> 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 | N | Reviewers noted that practice was good but this was not documented. |
| HP-595 | <p>Guidelines on Transition and Preparing for Adult Life</p> <p>Guidelines on transition of young people from paediatric to adult services should be in use covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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 | See Good Practice section of main report. |
| HP-599 | <p>Care of Vulnerable People</p> <p>Guidelines for the care of vulnerable children, young people and adults should be in use including:</p> <ol style="list-style-type: none"> 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 | <p>Service Organisation</p> <p>The service should have an operational procedure covering at least:</p> <ul style="list-style-type: none"> 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 in place. |
| HP-602 | <p>Multi-Disciplinary Team Meetings</p> <p>Multi-disciplinary team meetings to discuss patients' plans of care should take place regularly involving:</p> <ul style="list-style-type: none"> a. All core members of the specialist team (HP-202) b. Senior biomedical scientist or clinical scientist with responsibility for the Coagulation Laboratory c. HC staff who are regularly involved in the patient's care as part of network arrangements | Y | |

| Ref | Standard | Met? | Comments |
|--------|--|------|--|
| HP-603 | <p>Multi-Disciplinary Clinics</p> <p>The following multi-disciplinary clinic arrangements for patients with inherited and acquired bleeding disorders should be in place:</p> <ol style="list-style-type: none"> Involvement of medical, specialist nursing and physiotherapy staff in clinics Availability of social work and psychology staff in clinics Combined clinics or other arrangements for multi-disciplinary discussion with: <ol style="list-style-type: none"> orthopaedics rheumatology obstetrics and gynaecology paediatrics dental HIV / hepatology | Y | |
| HP-604 | <p>Liaison with Other Services</p> <p>Review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified.</p> | Y | |
| HP-701 | <p>Data Collection</p> <p>The following data should be collected:</p> <ol style="list-style-type: none"> UK National Haemophilia Database data on all patients Data on concentrate use and bleeds, either through Haemtrack or an equivalent mechanism Data required to complete the UKHCDO National Haemophilia Dashboard or other national mechanisms | Y | |
| HP-702 | <p>Audit</p> <p>The services should have a rolling programme of audit covering at least:</p> <ol style="list-style-type: none"> Clinical guidelines (QS HP-503) Emergency and out of hours care (QS HP-504) Initiation of prophylaxis in children Inhibitor surveillance and Immune Tolerance Induction (ITI) Clinical reviews including joint scores (QS HP-103 & 104) Concentrate use and wastage | N | There was a vast range of audit activity in evidence, but it did not cover the areas specified by this standard. |
| HP-706 | <p>Research</p> <p>The service should actively participate in research relating to the care of patients with bleeding disorders.</p> | Y | |

| Ref | Standard | Met? | Comments |
|--------|---|------|----------|
| HP-798 | <p>Multi-disciplinary Review and Learning</p> <p>The service should have multi-disciplinary arrangements for review of and implementing learning from:</p> <ul style="list-style-type: none"> 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 | <p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p> | Y | |

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Network

| Ref | Standard | Met? | Comments |
|--------|---|------|--|
| HY-199 | <p>Involving Patients and Carers</p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p> | Y | |
| HY-203 | <p>Inherited and Acquired Bleeding Disorders Network Leads</p> <p>The network should have a nominated:</p> <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse Lead physiotherapist Lead clinical or counselling psychologist Lead manager | N | Although a lead clinician was identified, leads for other members of the MDT had not been identified. |
| HY-204 | <p>Education and Training</p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HP-203.</p> | Y | |
| HY-503 | <p>Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ol style="list-style-type: none"> Diagnosis for patients with suspected inherited and acquired bleeding disorders (QS HP-501) Concentrate use and monitoring (QS HP-502) Clinical guidelines (QS HP-503) Management of patients with inherited and acquired bleeding disorders in the Emergency Department (QS HP-504) Care of patients requiring surgery (QS HP-505) Transition and preparing for adult life (QS HP-595) | N | Reviewers saw many good examples of shared guidelines, but not all the guidelines identified in the requirements of this Quality Standard. |
| HY-701 | <p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> Submission of data on all patients to the UK National Haemophilia Database (QS HP-701) Network-wide data on concentrate use and bleeds | Y | |
| HY-702 | <p>Audit</p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702.</p> | N | Excellent audit practice was evidenced, but the audits did not cover all the requirements of HP-702. |
| HY-703 | <p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with inherited and acquired bleeding disorders A list of research trials available to all patients within the network. | N | The review team agreed with the Centre's self-assessment for this standard. |

| Ref | Standard | Met? | Comments |
|--------|--|------|----------|
| HY-798 | <p>Network Review and Learning</p> <p>Representatives of Comprehensive Care Centres and referring Haemophilia Centres should meet at least once a year to:</p> <ol style="list-style-type: none"> 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 | <p>Commissioning of Services</p> <p>Commissioners should have agreed the configuration of clinical networks including:</p> <ul style="list-style-type: none"> 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 | <p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ul style="list-style-type: none"> 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 Qs | Y | |
| HZ-798 | <p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p> | Y | |

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