Inherited and Acquired Haemophilia and other Bleeding Disorders Peer Review Programme

Overview Report

Report Date: May 2020

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Executive Summary

1. This report presents the findings of the inherited and acquired haemophilia and other bleeding disorders (IABD) peer review programme that took place between November 2018 and January 2020. Thirty-seven sites were visited: all 28 Comprehensive Care Centres (CCCs) in England, Wales, Scotland and Northern Ireland, and nine[1] Haemophilia Centres (HCs).

2. The purpose of the visits was to review compliance with the Quality Standards for inherited and acquired haemophilia and other bleeding disorders (V1 July 2018), that were developed by the UK Haemophilia Centres Doctors' Organisation (UKHCDO) peer review working party working with the Quality Review Service (QRS)[2]. The standards were based on the NHS England (NHSE) Standard Commissioning Contract for Haemophilia (all ages) service specification[3], UKHCDO guidance, Haemophilia Society guidance and guidance from other professional organisations including the Haemophilia Nurses Association (HNA) and the Haemophilia Chartered Physiotherapists Association (HCPA). [4]

3. All of the reviews followed the same format and were undertaken by a multidisciplinary team of trained reviewers, together with a QRS assistant director and clinical lead who were both part of the team at all of the visits.

4. The findings presented in this report reflect those that were identified at the time of the visit. As the visits took place over a period of 14 months, action may have already been taken to address issues identified at earlier visits.

5. A glossary of terms and abbreviations is included in Appendix 3. A summary of the recommendations is included at Appendix 7**.**

6. A consistent theme across the Centres was that the professionals working in the service were enthusiastic, dedicated and highly committed to providing the best quality of care that they could for their patients. In all Centres, patients' feedback about the care they received from the specialist team was extremely positive. However, staff were often working in challenging circumstances because there was an under provision, and in some cases a complete absence, of key members of the multidisciplinary team (MDT). These staffing issues formed the majority of the concerns recorded by the review teams (see point 10 below).

7. Services for people with IABD fall under the responsibility of NHSE specialised commissioning. The CCCs, who provide 24-hour specialist treatment including 24-hour advice and support to the smaller HCs with which they are linked are expected to work together in networks, and the service specification explicitly refers to 'managed clinical networks'. The Quality Standards for inherited and acquired haemophilia and other bleeding disorders (V1 July 2018) included the expectation that networks should involve patients and carers, agree a programme of education and training, share guidelines, undertake shared clinical audits, monitor data, offer opportunities for access to research studies and hold shared review and learning meetings. Commissioners were expected to have agreed the network configuration, to review the quality of care provided by each service regularly and to attend network review and learning meetings.

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[1] The number of Haemophilia Centres visited was determined by the UKHCDO. These Centres included larger HCs and some who had no clear link with a CCC.

[2] When the initial programme was commissioned QRS was known as the West Midlands Quality Review Service (WMQRS). In July 2019 WMQRS completed a rebranding exercise and was thereafter known as the Quality Review Service (QRS). QRS is the name used for the purpose of this report.

[3] https://www.england.nhs.uk/wp-content/uploads/2013/06/b05-haemophilia.pdf

[4] The UKHCDO had previously undertaken external audits of Comprehensive Care Centres, every 3 to 5 years. These audits had taken place for over 20 years. This peer review process was broader and more comprehensive in its scope.

In practice, networks were found to be functioning at very different levels, with a few highly developed networks (including the Southern Haemophilia Network in south central England, the North West Yorkshire Haemophilia Network in Yorkshire and the Scottish Inherited Bleeding Disorders Network in Scotland), and some such as those in South Wales and the East Midlands taking active steps to work towards these standards. Where networks were functioning, the progress had mostly been led by interested senior clinicians, rather than commissioners.

In several areas, CCC staff appeared to be unaware that they were supposed to be working as the hub of a network. Many did not know that their services were commissioned by specialised commissioners, and they had not met or could not name their local specialised commissioning lead.

During the course of the visits, review teams spoke to senior staff at HCs and District General Hospitals (DGHs) supported by the CCC specialist teams, and almost all of these staff confirmed that they had 24/7 access to clinical advice for managing patients who presented to them. In all but a few Centres, other aspects of network functioning were elementary or non-existent.

8. There were seven immediate risks (at six Centres) identified during the course of the programme (full details are included in Appendix 5). In addition, there were 358 items of good practice, 89 concerns and 384 issues for further consideration. The total number of items of good practice identified at any particular site, or of matters for further consideration, must not be considered as a 'score', or necessarily as a reflection of the quality of the overall service, as the magnitude and significance of the issues identified varied widely.

9. All the immediate risks identified, although important, were issues that could readily be put right by Trusts. They included significant errors or omissions in clinical guidelines, members of staff not having up to date resuscitation training, and at one site nursing staff offering informal 24/7 contact to patients and families in an effort to support them, which was judged to put the staff at professional risk.

   All of the Trusts in which immediate risks were noted made formal responses to QRS outlining the immediate and longer term actions that they were taking to mitigate the risks, and in all cases, QRS confirmed that the actions taken had mitigated the risks identified.

10. The main concerns identified were:

    a. Staffing - patients should be managed by healthcare professionals experienced in the treatment of patients with haemophilia and other bleeding disorders, including consultant medical staff with a special interest, specialist nurses and specialist physiotherapists as the core team. Although there are no available workforce guidelines confirming the expected ratio between the numbers of staff in each professional group and the number of patients, the MDT was expected to include a clinical or counselling specialist psychologist or psychotherapist, a specialist senior social worker, a biomedical scientist and a data manager. Differing patient case-mixes, as well as the roles undertaken by administrative and clerical staff, data managers and service managers, have an impact on the needs in each team. Smaller services do not necessarily require proportionately fewer staff, as some duties, such as team meetings, service planning and improvement, maintenance of guidelines and policies, audit and other activities, are required in every Centre regardless of how many patients are managed.

       The under provision, or complete absence, of members of the core and extended multi-professional team was the most frequent and significant concern identified. Staffing concerns were reported at 23 of the CCCs and eight of the HCs. In most, there was a deficit in several of the expected professional groups. In two of the CCCs, the extent of the under provision constituted a 'serious concern'.

       In almost half of the CCCs, and over half of the HCs, specialist physiotherapy provision was either lacking or was far too limited to offer acute and long-term joint care for the numbers of children or adults being treated. In about two thirds of the CCCs, and the majority of the HCs, there was no named psychologist working in the team. Twenty of the 27 CCCs, and all the HCs, lacked a named social worker. Although specialist nurses were in post in all sites, in ten of the CCCs and half the HCs, reviewers considered that there were too few nurses to

manage their work sustainably. In nine of the CCCs, and in over half of the HCs visited, the senior medical time devoted to the service was judged to be insufficient, and this usually meant that while clinical services were adequately covered (if only just in some cases) other aspects of the service, such as audit, governance and improvement work, suffered. Finally, administrative and clerical support, and data management services, was frequently underprovided, with nurses' time therefore being taken up inappropriately on these non-clinical duties.

At the time of the visits, the inconsistency in the provision of key staff groups led to some inevitable inequity in the quality of care being provided.

Further detail on the specific staffing concerns is included below in the '200' Standards: Staffing' section.

b. Emergency Department (ED) care - patients often reported that they were not confident of the care they received in the ED, unless their specialist team members were on hand to guide this. In some Centres, clear guidelines for use by ED staff were lacking. Not all patient electronic records had an 'alert' indicating that a patient had a bleeding disorder.

c. Data – a few CCC's could not give accurate patient numbers (particularly for those with milder disorders) and activity data for their own Centre, and many did not hold data on the patients at their linked HC's or DGH's. Data sharing across networks was variable and often absent. The CCC therefore had no oversight of factor usage or key outcomes for patients at the linked Centres.

d. Clinical guidelines – at some Centres, these were not in useable form, or were sparse or missing. In other Centres, guidelines were in draft form and had not been ratified, and so were not available on the Centre intranet for use by staff.

e. Governance – only about one third of the Centres had an active audit programme to allow the teams to demonstrate performance in relation to some key clinical issues such as emergency and out-of-hours care, initiation of prophylaxis in children, and clinical reviews including joint scores. Review and learning activities were appropriate in most Centres, although discussions were not always minuted and there were sometimes no mechanisms to share learning across the team.

f. Environment and facilities – the quality of the physical spaces from which services were provided varied significantly. Many of the premises were welcoming, bright and spacious but others had very limited space and / or were difficult to access. In some Centres, the environment was so poor that reviewers felt it was of concern. Fridges in which factor concentrates were stored were not secure on three sites, and in one Centre there was no fridge temperature monitor, meaning the efficacy of the drug could possibly be compromised.

g. I.T. - many Trusts were in the process of transferring from paper to electronic records. In a small number, all previous records for a patient were scanned into a single file, which could reach hundreds of un-indexed pages. This meant that finding details of previous care episodes could be very challenging.

11. Specific good practice items are noted throughout this report under the relevant section[5]. Each individual report also reflected the key achievements of the Centre and these included strong MDT working in almost all Centres, by flexible, hardworking and committed individuals, who made every effort to be easily accessible to their patients. Exceptional contributions were being made by some team members; in many Centres, effective non-hierarchical leadership was also evident. In every Centre, patients' feedback about the care and support they received was good, and it was often extremely positive. Nine CCCs and three HCs were commended for actively seeking and making use of patient feedback, and active parent and patient support groups were running at several Centres. Team members often took time to organise out-of-hours training or social events for young people and families.

[5] The items of good practice highlighted have been selected at random from the individual Centre reports. It is not an exhaustive list of all 358 items identified across the full programme. The items selected aim to reflect the breadth of good practice seen.

The facilities from which services were provided were of especially high quality at one third of Centres. Support and engagement of laboratory scientists was excellent in many Centres. Some Centres were commended for the quality of the education and training they offered, over half for the patient information they provided, and just under half for the quality of their guidelines and other documents supporting the service. An active and wide-ranging research portfolio was seen in 16 of the CCCs.

12. The review teams, based on the reviewers' experience, highlighted issues for further consideration when they felt that a particular area may benefit from further attention by the service and that the implementation of the reviewers' suggestions could enhance the service. These issues also included some findings reported elsewhere as concerns, such as: where there were less significant staffing shortfalls; where some elements of data recording were inconsistent; where processes were not backed up by written policies or guidance, or the content of guidelines needed revision or clarification, or national guidelines were used without any indication of local application; where audit activity was low; where it was not clear how learning outcomes from incidents or complaint reviews were recorded or disseminated; or where facilities were poor, with small clinical or office areas, an absence of signposting or no convenient parking for patients.

    Patient information at some Centres was sparse, did not cover all diagnostic categories, and/or was not readily available in clinical areas. At some Centres, there were no established patient support groups, and little evidence that patients' and families' feedback on services had been sought or acted upon.

    In the care of long-term conditions, out of hours clinics are greatly valued by patients, as they allowed patients or their families to continue in work or education while managing their condition; however, such clinics were only available in a small number of Centres. For the better resourced Centres, where this might reasonably be managed, it was included as a further consideration. Similarly, outreach working, whereby staff from the CCC went to visit linked HCs to undertake clinics and thus saved patients and families from travelling long distances, was in place in a few areas and was raised for further consideration in some others where staffing levels would allow.

    In around half of the Centres, there was no robust process in place to ensure that obligate or potential carrier female relatives of male haemophilia patients were recalled for testing and counselling before they started their own families.

    At several Centres, patients indicated they were dissatisfied with the homecare service that delivered their factor concentrates for prophylactic or as-needed home use, finding it unresponsive and unpredictable and generally giving poor customer care.

    A comprehensive staff training competency and training record was often not available. In some Centres, a complete statutory and mandatory training summary was not available, or some less clinically important elements of staff training were noted to be out of date.

    The offer for patients to be recruited into research studies was not always being made, with associated loss of potential savings on factor concentrates or newer agents, and in several Centres the non-medical clinical staff were keen to be more involved in research.

    Support for Centre staff, by clinical and non-clinical managers, was noted to be poor in a small number of Centres.

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Introduction

1. Bleeding disorders are rare conditions in which one of the clotting factor proteins is either partly or completely missing. Clotting factor proteins play an important part in how blood clots. Haemophilia is the most widely recognised bleeding disorder. There are two main forms of haemophilia – haemophilia A (deficiency in coagulation factor VIII), with a birth prevalence of around 1:5000 males, and haemophilia B (deficiency in factor IX), which is less common, with a prevalence of around 1:30,000 males. In von Willebrand disease there is a deficiency or defect in the von Willebrand coagulation factor; this disease affects both men and women, is much more common (with a prevalence of at least 1:1000), is in most cases mild. These bleeding disorders are all inherited conditions. Other inherited bleeding disorders are uncommon deficiencies in other clotting proteins (factor II, V, VII, X, XI, XIII and fibrinogen), and some abnormalities of platelets, the cells in the blood which promote clotting. In this report, the conditions listed here, other than haemophilia A and B and von Willebrand disease, are grouped together as 'other conditions'.

2. Acquired haemophilia is a rare but potentially life-threatening bleeding disorder caused by the development of autoantibodies directed against plasma coagulation factors, most frequently factor VIII. Most patients with acquired haemophilia present with haemorrhages into the skin, muscles, or soft tissues and mucous membranes. The complex management of this condition was included within the scope of this programme.

3. Other common causes of increased bruising or bleeding are an acquired auto-immune condition known as Idiopathic Thrombocytopenic Purpura (ITP), liver disease, or anticoagulant medication. Management of patients with these conditions was not included within the scope of this programme.

4. Haemophilia A and B are 'X-linked' conditions, which means that girls and women who carry the haemophilia gene on one of their two X chromosomes are usually asymptomatic or mildly affected, whereas boys and men whose single X chromosome bears the altered gene are those who can be severely affected.

5. The normal range for factor VIII and IX levels in the blood is between 50 and 150 iu/dl[6], often expressed as 50-150%. When the level is less than 1%, the condition is severe, typically causing bleeding into the joints and muscles, often with no obvious cause. When the level is 1-5% the condition is referred to as moderate and bleeding usually occurs as a result of minor injury. When the level is above 5%, the condition is classified as mild with bleeding usually only occurring following injury, or surgery. Female carriers may have a level in this range, and often have heavy periods as well as increased risk of bleeding after injury or surgery.

6. The following table shows the number of patients who were registered at the Centres taking part in this peer review programme.

	Haemophilia A and B						Von Willebrand		Other		Total
	Severe		Moderate		Mild		Adult	Child	Adult	Child	
	Adult	Child	Adult	Child	Adult	Child					
CCC	1538	810	594	187	2555	669	6262	1448	7501	1772	**23336**
HC	186	55	67	24	420	84	1088	234	1233	246	**3637**
Total	**1724**	**865**	**661**	**211**	**2975**	**753**	**7350**	**1682**	**8734**	**2018**	**26973**

Table 1 *– Number of patients registered with inherited and acquired bleeding disorders.*

Source: Background information reports provided by each Centre: these figures do not include patients treated at HCs that were not visited as part of the programme.

[Note: 'Other' includes a wide range of patients, including patients for whom no diagnosis had been established. The ratio between the number of uncategorised 'others' and the number of severe haemophilia A patients varied

[6] International units per decilitre

between Centres from approximately 1:1 to over 10:1. Whilst a degree of case mix variation would be expected, this wide range suggests that some Centres included patients referred and investigated with no findings, and who may not actually have a bleeding disorder, in their figures under the heading of 'other'.]

7. The most common sites of bleeding are the joints and muscles of the limbs. Depending on the severity of the disease, bleeding episodes may be frequent and may be apparently without cause. In a child with severe haemophilia, the first joint bleed typically occurs when the child begins to crawl and walk, usually before he or she reaches two years of age. If inadequately treated, repeated bleeding will lead to progressive deterioration of the joints and muscles, severe loss of function, muscle wasting, pain, and joint deformity. These complications are minimised by appropriate factor replacement as necessary (see points 8 and 9 below), together with care and guidance from a physiotherapist specialised in the management of this condition.

   Rarely, babies with severe haemophilia can bleed into the brain, causing lasting brain injury. At any age, injury to the head has to be assessed and treated very promptly to avoid brain bleeding. Less commonly, bleeding can occur from the gut, or into the urinary tract.

8. Bleeding can be controlled or prevented by replacing the missing clotting factor in the blood through an infusion of clotting factor concentrate into a vein. The level of factor VIII or factor IX is increased temporarily so infusions need to be repeated. For some minor bleeding episodes one infusion may be enough to stop bleeding. For more serious bleeding, treatment may be needed for several days to keep the factor levels high enough to prevent re-bleeding.

9. In the 1970's and early 1980's, there was a major problem of transfusion transmitted virus infections, HIV and hepatitis C, from plasma derived concentrates. For many years now, all concentrates used in the UK for treatment of haemophilia A and B have been 'recombinant' – that is, synthetically manufactured – and do not carry the risk of transmitting infection.

10. Treatment with regular infusions of clotting factor, even where there is no obvious bleeding, is called 'prophylaxis' and aims to prevent the long-term damage caused by bleeding into joints and muscles. Prophylaxis aims to ensure the factor level in the blood is at all times sufficient to stop spontaneous bleeding, and it is usually offered to all severely affected individuals from a young age, typically between nine and 18 months of age. Research has shown that prophylaxis gives children the best chance to reach adulthood without damage to their joints. How often the infusions need to be given is decided for the individual but for standard half-life products, this is typically every other day for haemophilia A and two or three times a week for factor IX, which lasts a little longer in the blood. New long-acting factors that need to be given less often are now available – these are known as 'extended half-life' treatments.

11. The vast majority of people with severe haemophilia and some with moderate haemophilia learn to treat themselves or their children with clotting factor at home. Home treatment makes regular prophylactic treatment possible and ensures treatment can be given as soon as possible after clinically apparent bleeding starts. Teaching families and patients how to administer factor at home is one of the roles of the specialist nurse.

12. An important extra complication develops in some individuals – formation of an inhibitor. This is an antibody that the immune system (the body's defence mechanism) develops when it recognises the clotting factor being used in treatment as something foreign. The inhibitor removes the clotting factor before it can work to stop any bleeding. Inhibitors usually affect approximately a third of small children with haemophilia A usually within the first 20 exposures to treatment, but they can also occur later in life and in milder forms of haemophilia. They are much more unusual in people with haemophilia B. There are clear guidelines as to how often children and adults need to be screened for the development of inhibitors.

13. Sometimes, higher doses of clotting factor can have some effect in stopping bleeding when inhibitors have developed, but usually an alternative by-passing treatment is needed. The conventional options are factor VIIa and activated prothrombin complex concentrate which can be used to treat or prevent bleeds. There is also a treatment called immune tolerance therapy (ITT) that aims to get rid of the inhibitor so that the person can return to standard haemophilia treatment.

14. A new agent called Emicizumab which is simpler to give and is given by subcutaneous injection usually once a week or once a fortnight, has been approved for use in the management of patients with haemophilia A and inhibitors, and more recently also for prophylactic use in those with severe haemophilia without inhibitors. Patients with inhibitors who suffer a bleeding episode can be treated by 'by-passing' agents such as activated prothrombin complex concentrate (aPCC, marketed as FEIBA). Once a patient is on treatment with Emicizumab they should not be administered aPCC additionally, as there is a risk of forming unwanted clots within the circulation. Instead, recombinant factor Vlla (NovoSeven) may be used.

15. In the UK, patients with bleeding disorders are cared for by staff with specialist skills in treating and managing these conditions. Care is provided by Haemophilia Comprehensive Care Centres (CCCs), which usually provide care for at least 40 severely affected patients. CCCs provide 24-hour specialist treatment, including 24-hour advice and support to the smaller Haemophilia Centres (HCs) with which they are linked. Patients should have access to clinical services provided by healthcare professionals experienced in the treatment of patients with haemophilia and other bleeding disorders, including consultant medical staff with a special interest, specialist nurses and specialist physiotherapists as the core team. The MDT is also expected to include a clinical or counselling specialist psychologist or psychotherapist, a specialist senior social worker, a biomedical scientist and data manager.

16. There are no available workforce guidelines as to the required ratio between the numbers of staff in each group and the number of patients. Differing patient case-mixes, as well as the roles undertaken by administrative, clerical and data management support staff and service managers, have an impact on the needs in each team. Further, smaller services do not necessarily require proportionately fewer staff as some duties such as team meetings, service planning and improvement, maintenance of guidelines and policies, audit and other activities are required in every Centre.

17. There are 28 CCCs in the UK that provide specialist advice and treatment for patients with bleeding disorders. In some cities there is a combined CCC treating adults and children, whereas in others, adult and paediatric services are provided by separate CCCs. In addition, there are 41 HCs. They are smaller in terms of the number of patients registered and the size of the MDT. All HCs are linked to a CCC for complex referrals, for obtaining specialist advice and for networking and commissioning arrangements.

18. This programme was commissioned by the United Kingdom Haemophilia Centres Doctors' Organisation (UKHCDO). The UKHCDO is an association of medical practitioners who work in the Haemophilia Centres of England, Scotland, Northern Ireland and Wales and have an interest in the care of people with haemophilia or other inherited bleeding disorders.

19. Finally, QRS wishes to express their sincere thanks to all colleagues in the CCCs and HCs for their cooperation with the programme, for their openness and honesty during the course of the reviews and for offering their time to be reviewers. Our thanks are offered too, to the administrative team at the UKHCDO offices who managed the travel arrangements for many of the reviewers.

    We are especially grateful to the many patients and carers who supported the programme as reviewers and those who also took the opportunity and gave their time to meet with review teams and share their experiences of the Centres that they attend.

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Peer Review Programme

1. Preparation for the programme started in 2015, when the UKHCDO started discussions with QRS. Approval for the programme to proceed was given by the UKHCDO advisory committee in May 2017. The agreed scope was to assess the quality of services provided by the 28 CCCs and nine of the 41 HCs across the UK. A list of the Centres reviewed is included in Appendix 2.

2. A peer review working party was established, chaired by Dr John Hanley, the Centre Co-director at the Newcastle NHS Foundation Trust, with representatives from CCCs and HCs across the United Kingdom. This group was multi-disciplinary with members from a range of professional staff groups. It also included patient representatives and representatives from the Haemophilia Society (England). A list of its members is included in Appendix 1.

3. The group worked with QRS to develop a set of Quality Standards for the programme. The development of the standards followed the QRS standard methodology, which is available on the QRS website[7]. A list of the titles of the Quality Standards' is included in Appendix 4, and a full set of the Quality Standards is available on the UKHCDO and QRS websites.

4. The aim of the Quality Standards is to improve the quality of care for people with inherited and acquired haemophilia and other bleeding disorders and to help answer the question: 'At each point on the pathway, how will I know that national guidance and best practice has been implemented'?

5. Through the implementation of the Quality Standards it is intended that:

   a. The local community, service users and carers will know more about the services they can expect.

   b. Commissioners will be supported in assessing and meeting the needs of the population, improving health, and reducing health inequalities, to improve service specifications.

   c. Service providers and commissioners will work together to improve service quality.

   d. Service providers and commissioners will have external assurance regarding the quality of local services.

   e. Reviewers will learn from taking part in the reviews.

   f. Good practice will be shared across the Centres.

6. The Quality Standards are related to the care of people with inherited and acquired haemophilia and other bleeding disorders (IABD), which include haemophilia A, haemophilia B, von Willebrand disease, inherited platelet disorders and other rare inherited bleeding disorders.

7. Invitations to join review teams were issued to staff at Centres as well as to relevant professional groups, including the Haemophilia Society, the HNA and the HCPA. All reviewers were required to attend a face to face or online training session prior to joining one of the review teams. In total, 20 training sessions were delivered (nine face to face and 11 online) over a six-month period between August 2018 and January 2019.

   The following table identifies the number of people, by profession, trained in the peer review process for this programme:

	Face to Face	Online	Total
Medical Staff	11	34	45
Nurse	46	21	67
Physiotherapist	20	11	31
Psychologist	1	4	5

[7] https://qualityreviewservicewm.nhs.uk.

	Face to Face	Online	Total
Manager	0	8	8
Biomedical Scientist	0	3	3
Patient / Carer	7	12	19
Social Worker	1	3	4
Total	**86**	**96**	**182**

***Table 2** – Numbers of reviewers trained by professional group: Note - not all those trained attended a review and some attended more than one review.*

8. Review teams included trained peer reviewers from Centres across the UK. All the teams were multi-disciplinary, and they varied in size according to the size and scope of the Centre being reviewed. In addition, Centres that were based across more than one site generally had a larger visiting team, in order to ensure that all the relevant information could be assessed, and all appropriate facilities viewed. All teams included, at least, a consultant haematologist, a nurse specialist, and a physiotherapist working in the specialty.

   The QRS lead for this programme was Rachael Blackburn (QRS assistant director), and the clinical lead for the programme (working with QRS) was Dr Anne Yardumian, a consultant haematologist with previous experience of working with QRS on a range of peer review programmes. Both attended all of the reviews, to ensure that consistent application of the standards could be achieved.

9. The 37 peer reviews took place between November 2018 and January 2020. All the visits followed a standard format with an initial presentation from the host Centre, a detailed review of available documentary evidence, and a visit to the environment and facilities from which care was delivered. Meetings then took place with the Centre teams, other speciality colleagues, other stakeholders and patients / carers. At three of the visits meetings also took place with commissioners.

10. At the end of the review day, a feedback meeting took place with the host team and other invited clinical and non-clinical members of the Trust team, to give high level feedback on the findings from the review.

11. At a few of the CCC reviews it was possible to meet, or talk on the telephone to, colleagues from linked HCs that were not visited, but services at the remaining 32 HCs were not assessed in any detail and are therefore not included in this report.

12. Following each review, a draft report was circulated to the review team members for them to check its factual accuracy before it was then updated and sent to the team at the Centre, for them to check its factual accuracy. Appendix 8 summarises the reporting timeline.

13. Once the draft report had been updated, it was presented to the QRS Quality Assurance Group (QAG) for final approval. QAG is an internal quality review group that QRS has in place for the final sign-off of all its reports. The group is made up of senior NHS professionals and lay members. For the purpose of this programme, Rachael Blackburn (QRS programme lead) and Dr Anne Yardumian (clinical programme lead), as well as a UKHCDO representative, attended in order to provide expertise from an IABD perspective.

14. The final version of the reports was then sent to the Centre director so that the findings of the review could begin to be actioned and could be shared with Trust colleagues, networks and commissioners.

15. It was agreed with UKHCDO that all of the individual Centre reports would be published and made publicly available at the conclusion of the full programme.

16. An important part of any QRS review programme is that the voice of patients and those who care for them is sought and listened to. In this report, the term 'patient' encompasses patients, those who care for them, parents of children using a service and those who may use a service but do not identify themselves as patients.

Each review team included a patient representative who had been trained in the peer review process prior to being invited to join a review team. In total, 15 patient representatives attended the reviews (meaning that some attended more than one). They all gave their time freely to be part of the programme, engaged with those using the service and checked the draft report. Their support was invaluable in ensuring the reviews were robust.

Each review timetable included a meeting with patients and those who care for them. This was an open discussion led by the patient representative on the review team with the purpose of seeking the views of patients about the care and support that they received from their Centre. Some patients were not able to attend in person but asked for a telephone call which was facilitated during the course of the review. QRS did not identify those who were invited, and it was at the discretion of the service to ensure the review was widely publicised.

We are grateful to all those patients who made time to join these meetings; some of whom made an additional journey to the hospital to do so.

The specific comments and views from service users have been included in the following sections of the report, as part of the review teams' findings; however, it is appropriate to understand the themes that the reviewers heard.

17. In all cases, patients were overwhelmingly positive in their feedback about the care they received from the specialist MDT members and were keen to express their gratitude. Patients had respect for their specialist team and had developed a good relationship with them. They recognised that where staffing shortages occurred, the specialist teams were trying hard to minimise the impact on patients.

    The staff in the specialist teams recognised that bleeding disorders are a long-term condition, and that patients were expert in their own condition and its management. Patients told reviewers that sometimes, when they received services from those outside their specialist team (for example the ED), their knowledge of their own condition was not always recognised.

    Patients were able to access advice and support out-of-hours, although this was not always easy. Patient information was usually comprehensive and well presented, and some Centres had invested in on-line technology for sharing information and providing training to schools. Telephone and 'Skype' clinics were also available in one Centre, which improved the patient experience by reducing the need for patients to travel for all consultations. This improved the experience of patients using the service.

    In many cases, there was active patient and public involvement that helped drive change and improvement. In many Centres, patient views were actively sought, and some Centres arranged extra activities (exercise classes, children's parties and social events). However, these changes were not always shared back with patients, nor was it always clear what change had occurred because of the feedback.

    Many patients mentioned the problems associated with car parking. Some patients may be attending with an acute joint bleed which makes walking any distance difficult, and other patients may have mobility issues. However, it was recognised that this was outside the direct control of CCCs and HCs.

    Reviewers heard that Centres need to do some further work in ensuring that care and support is available for carers and those who support patients with bleeding disorders.

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Findings

1. The following sections summarise the findings from the 37 visits, highlighting good practice and providing recommendations for future action, with the aim of improving the quality of services being provided. The findings are presented in line with the relevant sections from the Quality Standards.

   The following table summarises the number of findings (by category) from all of the Centres reviewed:

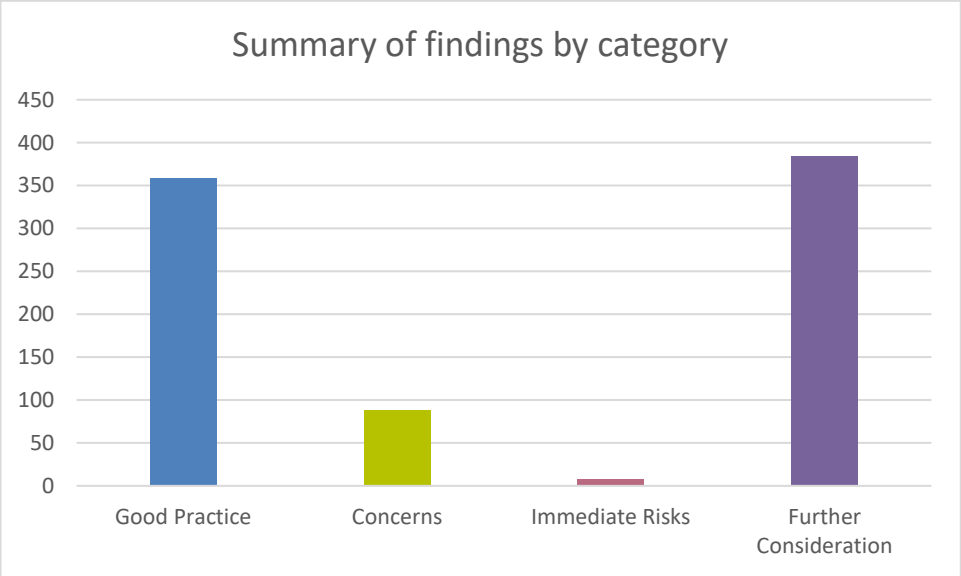

Table 3 *– Summary of key findings from all visits*

The reviews identified 358 items of good practice, 89 concerns and 384 issues for further consideration.

In addition, there were seven immediate risks identified (at six Centres) during the course of the programme. Full details of each immediate risk are outlined in Appendix 5. An immediate risk is defined as a potential Serious Incidents (SI), that is, a situation in which an SI could occur in the circumstances found by the reviewers. Immediate risks require urgent attention and a formal response by the Trust.

When an immediate risk was identified during the course of the programme, each of the relevant Centres was extremely cooperative and responsive in providing a formal update to QRS to identify what action had been taken to mitigate the risk.

2. The following tables shows the number of findings for the CCCs and HCs.

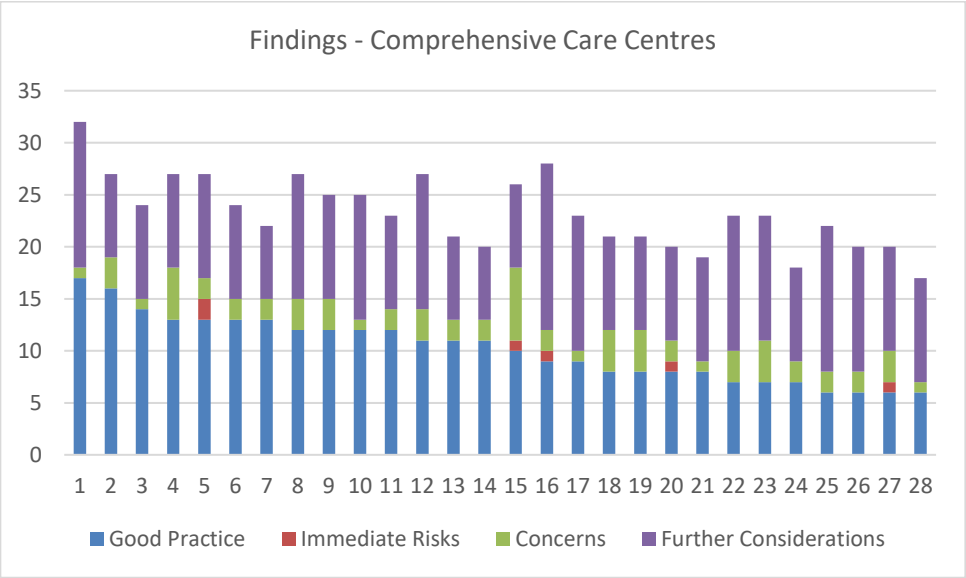

Table 4 *– Review findings by Comprehensive Care Centre*

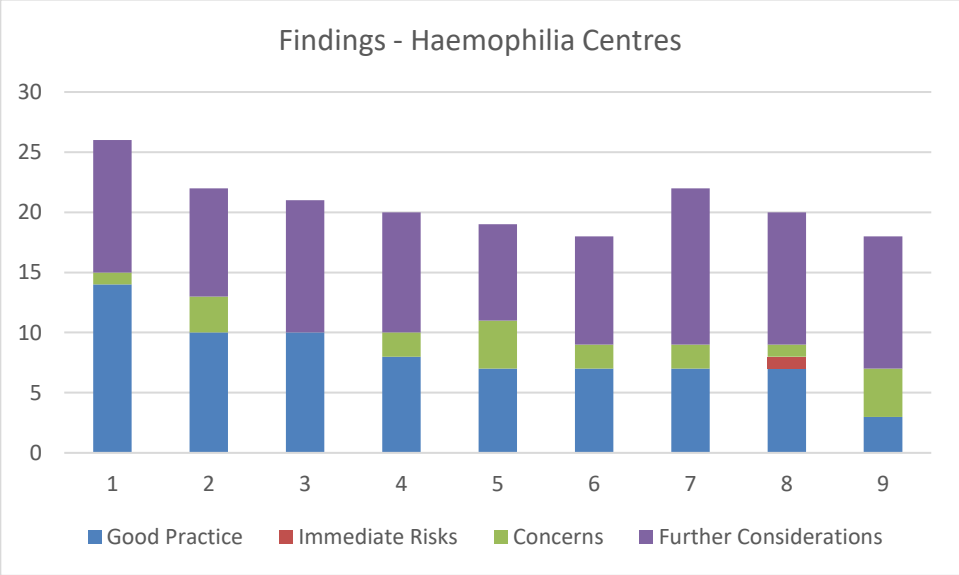

Table 5 *– Review findings by Haemophilia Centre*

[Note: – the number of findings must not be taken as 'score' or an indication of the quality of the service being delivered at a Centre. In a Centre at which the service was extremely well managed, the further considerations focussed on detailed points that may not have been relevant at other Centres. Similarly, in Centres that were not as robust, the further considerations focussed on significant issues rather than matters of detail. Comparisons of the number of findings are, for this reason, not appropriate].

3. For each review, a detailed narrative report was produced which also included a list of the standards and the Centre's compliance against each, as agreed with the review team and the Centre. These full reports are now available on the QRS website – www.qualityreviewservicewm.nhs.uk/reviews

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100 Standards: Information and Support for patients and carers

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-101	Service Information	34	3	0	92%
HP-102	Condition-specific information	31	6	0	84%
HP-103	Plan of care *	27	9	0	73%
HP-104	Review of plan of care *	29	7	0	78%
HP-105	Contact for queries and Advice	37	0	0	100%
HP-106	Haemtrack (patients on home therapy) **	35	0	2	95%
HP-194	Environment	29	8	0	78%
HP-195	Transition to adult service and preparation for adult life	30	7	0	81%
HP-198	Carers' needs	21	16	0	57%
HP-199	Involving patients and carers	28	9	0	76%

Notes:

*Southampton CCC was not assessed for Quality Standard HP-103 and HP-104 as the CCC did not obtain Caldicott Guardian permission for reviewers to look at patients notes prior to the visit.

**At the time of the peer review programme Haemtrack was not in place in Northern Ireland (two Centres).

Summary

Information and support for patients and carers was in place in most centres, and there were several examples of good practice.

All patients and their families knew who to contact to discuss issues relating to their condition, both in and out-of-hours.

Ongoing work was needed to ensure that available information was actually given to patients and carers.

More structured collection and use of patient feedback was required at many sites.

Some Centres provided valuable support and signposting to other services for carers and families, but many needed a better focus on the needs of carers and families, as well as their patients.

1. This first group of standards focus on the written and practical support provided for patients and their families. Information for patients and carers was of a high standard overall. Patients, parents and carers whom reviewers met were confident that they knew who to contact routinely, and in an emergency, both in and out-of-hours. There were several examples of good practice in the quality of service information, covering all necessary details.

2. This group of standards also focus on plans of care. Assessment was made as to whether reviews were being completed in line with national guidance (every three months for children under five years, every six months for severe adult patients and annually for all other patients). This standard also required that copies were sent to patients' GPs, and patients, following their routine review.

   Care plans were in place for most patients, and the majority of patients had their routine reviews in line with national guidance. However, the detail contained in the plans was variable and reviewers heard from patients that there was inconsistency as to whether they received a copy of their care plan, or clinic letter in which it was summarised, following a consultation.

3. Haemtrack® is a secure national system that enables patients to record, via a website or app, their bleeding episodes and the factor they self-administer on each occasion. This allows clinicians to see up-to-date information and helps

them to monitor and improve care. At the time of the review programme, Haemtrack was not in place in Northern Ireland although there were plans to introduce it in early 2020.

In all other Centres, completion of Haemtrack was actively encouraged by staff, and a number of Centres proactively reviewed Haemtrack data to check whether a patient had entered information and to contact patients to follow up when their entries indicated they had suffered a bleeding episode at home.

4. At each of the Centres, the review team visited the facilities in which patients were treated and cared for. The visits included the Emergency Department (ED), outpatient, day care and inpatient facilities, where appropriate, to ensure that the full patient pathway was reviewed.

   The quality of the environments in which patients were treated varied considerably. Twenty-nine Centres had access to premises and equipment that enabled them to provide effective care and a positive patient experience. Facilities varied, with some clearly signposted and dedicated haemophilia centres and some teams who were providing care from cramped treatment rooms and office space which prevented full MDT working (as treatment rooms were too small) or a positive patient experience (in one case, treatment was being provided in waiting areas where other patients and their families were present so privacy and dignity could not be maintained). In two Centres, although the premises were adequate at the time of the visit, the teams reported that they had been told by their Trusts that they would be required to move to alternative, less appropriate, premises in the near future.

5. Overall, the vast majority of patients reported that they were very happy with the environments in which they were receiving their care and treatment though many did comment on the significant difficulties that they had with parking near their Centre.

6. Transition is the process by which young people move from receiving their care from the paediatric service to receiving it from the adult service. The age at which full transition takes place will vary between services, but it generally starts with discussions and education in the patient's early teens, and finally takes when he or she is around 16 to 18 years of age. The key to this standard is that the patient's transition is managed well and that the patient, and where appropriate his or her family is fully informed at each stage of the process.

   Quality Standard HP-195 focussed on the written and verbal information available for patients. Most Centres had access to a Trust transition policy (that covered all long-term conditions) and many used the national 'Ready, Steady, Go' programme. Twenty-nine Centres were judged to be providing robust information to support young people through the transition process.

7. The needs of carers were not routinely considered and assessed. Many patients reported that the staff asked about their relatives and support networks but in many Centres, there was no routine assessment of carers' needs, or signposting to other Trust or community carer support networks.

8. Some teams had made particular efforts to engage with their service users when planning services, and to try to improve the user experience in response to feedback. However, other than a few questionnaires that had been specifically given to patients in preparation for the peer review, many Centres did not routinely seek the views of their patients and families.

   Most patients whom reviewers met said they would feel confident about giving informal feedback to their teams, which is positive, but a more formal mechanism is also necessary to obtain feedback, particularly from patients who may not volunteer their views.

Recommendations

1a. Teams need to ensure that service and condition–specific information is available in different formats and that it is routinely given to patients, particularly those who have attended the Centre for some time, as information and contact points may have changed since the patients received information when they were first diagnosed.

1b. Care plans and clinical letter proformas should cover all the main elements of Quality Standard HP-103, and should routinely be copied to patients, and parents or carers of children.

1c. Efforts are needed to ensure that appropriate office space for staff to work from, and clinical treatment space is available.

1d. Further work is needed on providing clear signage to Centres. Although most patients have been attending their Centre for many years and knew where to go, this would not always be the case for new patients.

1e. Consideration should be given to providing designated parking spaces close to the Centre. Some patients may be attending with an acute joint bleed which would make walking any distance difficult, and other patients may have mobility issues.

1f. All Centres should ensure that the transition process is carefully managed, and that young people and their families are fully informed and supported at every stage of the process. This will help to improve patient experience and continued adherence to treatment during this vulnerable stage.

1g. Centres are encouraged to ensure that there is a greater focus on carers needs and improved access and signposting to services that are widely available through the Trusts or via other third party and charity sectors.

1h. A more formal mechanism for inviting feedback from all users, who may not volunteer their views, is recommended to inform service improvement. When issues are raised, efforts should be made to address them, to implement appropriate change where possible, and to communicate any changes back to service users: 'You said, we did'.

1i. The Specialised Blood Disorders Clinical Reference Group should lead a review of the homecare delivery service in order to ensure that patient experience is improved, and the service is more responsive to patient needs.

Good Practice

Alder Hey Childrens CCC

- There were some excellent locally written information leaflets for patients, parents and carers, including condition-specific information and information for schools and first aiders.
- Annual user satisfaction surveys had been undertaken over the last six years, with evidence of changes made as a result of comments received.

Basingstoke CCC

- There was a 'carer's hub' providing support as needed, and excellent support from team members for parents using the service, even if their concerns were unrelated to their child's condition.

Belfast Adults CCC

- Noted were a *Welcome to the adult service* pack for young people on transition from the paediatric service based at the Royal Belfast Hospital for Sick Children; a *Playing it safe* leaflet encouraging physical activities within safe limits; and a *single assessment tool* which patients were asked to complete while waiting for their clinic consultations and in which they recorded any aspects of their physical or mental health that they wanted to discuss during their consultation.
- The social worker wrote excellent detailed guidance for each patient applying for Personal Independence Payments (PIP).

Belfast Children's CCC

- Full information packs, individualised by condition and severity, were available for children and families joining the service.

Birmingham Adults CCC

- Patient information was comprehensive, with an outstanding small laminated guide *Caring for patients with a bleeding disorder*, and good advice about dental care. Some patient information was marked by 'traffic lights' for clarity and ease of understanding. There was an excellent guideline for patients self-treating at home, with a detailed competency assessment section.

Cambridge CCC

- There was a support group for parents of recently diagnosed babies, and children under the age of two.

Canterbury CCC

- Plentiful patient information, a comprehensive description of the service, and full condition-specific folders of information were prepared for each patient. There was a detailed and clear guideline and competency framework for the safe administration of clotting factors at home.
- Patient feedback on the service was regularly sought, and findings were displayed in the clinic waiting area. There was evidence of several changes made in service delivery as a result of patient comments. Informal 'coffee mornings' were held so that patients could discuss any issues they had. These also served as a support group.
- Children were taken on a tour of the laboratory, so they could see what happened to their blood samples, reflecting unusual thoughtfulness about what they might find interesting and what could help de-mystify the process.

Cardiff CCC

- The team were very active in obtaining patient feedback, including arranging regular focus groups. Patient events were held, attended by team members, including an engaging and educational event with the Cardiff City football team.
- The care of older children and young adults was a focus of attention, with the establishment of a 'high school clinic' for those over 11 years. Inpatient beds for these patients were in a specific teenagers and young adults ward area.

Glasgow Adults CCC

- 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.

Great Ormond Street CCC

- Written information for patients was comprehensive; some of it derived from national leaflets but adapted and badged for local use and some of it was novel, written by local team members. This included information regarding managing joint bleeds, and an information sheet about early detection and management of brain bleeds which had been adopted by other Centres.

Guy's and St Thomas' CCC

- Carers' needs for both the adult and paediatric services were supportively managed.

Hull HC

- Patients' feedback comments, and actions taken in response to them, were displayed and updated every month.

Imperial HC

- A recent patient survey had been held with high response rates and very positive feedback about the services. The comments were carefully analysed and presented, and some changes were made in response to patient and carer suggestions.

Leeds CCC

- There was active patient involvement, with regular meetings of a Patient and Carer Involvement Group, and plentiful examples of changes made in response to patient and family feedback. The physiotherapy team gave energetic input to these activities.
- A service information leaflet for the children's service was in a form that enabled the information to be translated into a wide range of languages.

Leicester CCC

- The ward area available for the use of teenagers and young people was of a very high standard.

Manchester Childrens CCC

- Several noteworthy guidance documents included: a *Home care charter*; a guideline on factor ordering, storage and stock control; a parent and carer competency document for children on home treatment; a letter to families from the social worker outlining what she could offer; and an excellent detailed individual healthcare plan for schools which included multiple carer contacts, indicating who could give factor replacement and so could most usefully be called if the child had an accident or bleed while at school.

Oxford CCC

- There was active patient and public involvement, including various support groups, social outings, and a regular patient newsletter.

Plymouth HC

- A clear and useful leaflet on inherited platelet disorders had been developed by the Clinical Nurse Specialist.

Royal London CCC

- Some very good written information was provided to patients, including the patient service information booklet.
- A comprehensive 'app' had been developed by the service that included a great deal of information and guidance.

St Georges HC

- Some excellent documents supported the service, including *How does physiotherapy help my haemophilia* and *Sports, exercise and activity in haemophilia*.
- A letter for adults and children explained their diagnosis and the need to avoid intramuscular injections and non-steroidal anti-inflammatory drugs.
- There was a general letter for GP's, *Caring for children with inherited bleeding disorders*, a comprehensive school care plan, and information transfer letters for patients visiting general dental practitioners, and for young people moving away from home to undertake higher education.

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200 Standards: Staffing

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-201	Lead Consultant and lead nurse	34	3	0	92%
HP-202	Staffing Levels and Skill mix	8	29	0	22%
HP-203	Staffing competencies and training plan	12	25	0	32%
HP-204	Competencies – all health and social care professionals	29	8	0	78%
HP-299	Administrative, Clerical and Data collection support	28	9	0	76%

Summary

Staffing levels were the greatest and most consistent concern in this review programme. In some Centres they constituted a serious concern.

All the Centres had a lead consultant and lead nurse who were responsible for the day to day delivery and future development of the service. However, the time available for the individuals to undertake their leadership roles was not sufficient in many Centres.

The availability of specialist physiotherapy support, and psychosocial care, was inadequate in many Centres.

Whilst most Centres had robust procedures in place for recording statutory and mandatory training, few were able to identify the specific training requirements and core competencies for members of the haemophilia MDT (HP-203).

Of those standards which relate to clinical care and delivery, the ones relating to staffing levels, skills mix, competencies and training achieved by far the lowest compliance.

1. This group of standards focus on whether the Centres had the appropriate staffing levels, skill mix and training in place in order to deliver care to patients.

2. Staffing levels for existing patient numbers were the greatest and most consistent concern for services in this review programme. In some Centres this constituted a serious concern. The problem was exacerbated by the recent increase in patient numbers that was being experienced by most Centres. Taken in conjunction with the anticipated loss of established consultants and nurses to retirement over the next few years and the shortage of newly trained individuals to replace them there are significant concerns about the sustainability of many services in the coming years. In addition, it was clear from the review visits that nursing staff with specialist training in bleeding disorders were difficult to recruit.

3. In one Centre, an immediate risk was identified in relation to the protection of staff and the advice that they were providing. In their efforts to provide support for children and families, the two nurses offered an informal out-of-hours service, receiving calls from families during evenings and weekends. This was the process outlined in the departmental operational policy. While this posed no risk to patients, it put the nurses individually at risk as organisations may not support or indemnify professionals for advice given when not on duty.

4. Training was identified as an immediate risk in two Centres. In one Centre, children were sometimes treated by adult trained nurses who lacked paediatric resuscitation and life support training and a paediatric doctor (who did have Advanced Paediatric Life Support training) was not always present and there was no clear guidance in place as to how the paediatric resuscitation team should be called. There was therefore a risk that the start of appropriate resuscitation efforts could be delayed. In another Centre 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 may receive blood transfusions, and factor administration, which could give rise to anaphylaxis.

5. All Centres had a named consultant and a lead nurse in place who were responsible for the day to day delivery of care, and the management and development of the service. These individuals were well known to patients, who recognised their leadership roles.

6. HP-202 focussed on whether there was sufficient staffing in the MDT, with an appropriate skill mix to deliver the service and support its future development. Although there are no specific national guidelines in place that define the numbers of staff hours that are deemed appropriate for patient numbers, the Quality Standard considered medical, nursing, physiotherapy, psychosocial, administrative and clerical, and laboratory input. The standard also focused on the on-call arrangements, the arrangements for covering sickness / absence and the support available from other haematology colleagues in the wider Trust.

   Reviewers found appropriate levels of staffing and skill mix in only eight Centres (22%). It should also be noted that of these eight Centres that did have 'adequate' staffing, four were Centres where network arrangements were well established. Network arrangements will be discussed in more detail later in this report, but well-established networks were seen to enable the effective implementation of shared posts and allow for cross cover between Centres during time of sickness or other absence.

7. In relation to senior medical staff, all CCCs and HCs had consultant staff leading the service, and a named director. However, the time allocated to the role varied enormously, with no specific time being included in the job plans in some cases. In two HC's, the paediatric service was being led by an adult haematologist, without sufficient support from a paediatrician, and in one CCC there was no paediatrician or paediatric haematologist leading the children's service at the time of the visit. In over half of the HCs visited, and in nine of the CCCs, the senior medical time devoted to the service was judged to be insufficient, and this usually meant that while clinical services were adequately covered (if only just in some cases) other aspects of the service, such as audit, governance and improvement work, suffered. In only a very few cases was any time identified to manage expected network activities.

8. The role of the specialist nurse is paramount. CNSs are the front line of bleeding disorder care; they are the main point of contact for patients and families and, as a result, help shape services for each patient according to their choice. CNSs work closely with the wider clinical teams in their local Trusts and in the wider network, facilitate the pathways for patients being admitted for surgery, manage bleeds and help patients maintain independence with their long-term condition. They conduct clinics, enable home treatment, and provide education to both healthcare professionals and those affected by bleeding disorders. In addition, many CNSs participate in research, hold management responsibilities and care for individuals with additional haematology conditions.

   Although there were specialist nursing staff in post at all the sites visited, in ten of the CCCs and half the HCs, reviewers judged that there were insufficient numbers of staff in post to manage their work sustainably. Many CNSs were working additional unpaid hours to try to meet the needs of their patients, some had not felt able to take their annual leave, and several were anxious about taking time out for training as they were concerned about who would cover their work while they were away from the Centre.

   The nurse specialists were singled out for special mention by almost all the patient groups who met with the reviewers.

9. In almost half of the CCCs, and over half of the HCs, specialist physiotherapy provision was either lacking, or was far too limited to offer acute and long-term joint care for the numbers of children or adults being treated. All guidelines recognise the importance of physiotherapy within the acute setting, for the management of bleeds, in the ongoing monitoring of joint health and function, and in helping to improve musculoskeletal health on a long-term basis. Without adequate input from this key professional group, joint health of children and adults with bleeding disorders is at risk.

10. In about two thirds of the CCCs, and the majority of the HCs, there was no named psychologist working in the team. Patients with bleeding disorders, and their family members, often have complex psychological issues requiring specialist counselling or clinical psychology input. Without this specialist team member, patients and families could usually be referred to a general hospital or community psychology service, but waiting times were long, and general

services lack staff with an understanding of the specific problems that patients face with these conditions. Referrals were often made only for the highest-level needs, with lower level issues being managed by other team members such as the nurse specialists, or not at all. In addition, where there was a psychologist as a member of the core team, they often brought additional support to the other specialist staff in the team. This meant that most teams were therefore lacking this important resource.

11. A specialist social worker can help individuals cope with the physical and psychological effects of illness and treatment, manage family issues, establish contact with appropriate organisations, and manage transition, as well as providing support and advocacy with work, study, benefits and housing. In 20 of the 27 CCCs, and all of the HCs, visited, there was no named social work member of the team. In many instances, already over-stretched nurses were trying to help with these issues, often to the detriment of their clinical duties.

12. A great deal of complex information is required to manage bleeding disorder services, including ensuring up to date completion of a dataset for each patient on the National Haemophilia Database and the recording of factor issue and usage, bleed frequency, joint scores and other outcome measures. Most Centres also use the Haemophilia Clinical Information System (HCIS). Sufficient staff to manage, record and submit data were lacking at many Centres, with nurses' time therefore being inappropriately taken up with these non-clinical duties.

13. In nine Centres, it was identified that there was insufficient administrative and clerical support available to the team. This meant that nursing time was being directed towards administrative tasks such as typing clinical letters, booking routine patient appointments or uploading data, often when their time was already stretched.

14. HP-203 focuses on the training plans and record of competencies that are identified for members of the MDT. Many Centres had not understood what was required to demonstrate compliance with the standard, which notes that there should be *'a matrix of roles within the service, identifying the competencies needed for each role, whether these had been completed and plans to achieve them, where appropriate'.*

    Only 12 Centres (32%) provided appropriate evidence of a training plan for the members of the core team.

15. Most (29) Centres were able to demonstrate that their staff were compliant with their statutory and mandatory training. However, in two, lack of compliance with resuscitation training was identified as an immediate risk (see Appendix 5).

Recommendations

2a. Meeting staffing and skill mix requirements in teams managing IABD services is a national challenge that needs to be urgently addressed. Stronger networking arrangements, and improved commissioner engagement, will be required if progress is to be made.

2b. A review of job descriptions and plans for staff currently in post is required to ensure that they have the appropriate time to undertake their leadership roles, as well as the necessary training and professional development.

2c. A guide to the minimum ratios of the number of staff to the number of patients treated, outlining the time required for key tasks for each role, should be developed by UKHCDO / the Specialised Blood Disorders Clinical Reference Group as a key resource to support Centres in responding to these challenges, and progress should be made towards a commissioned workforce plan. This must include all key MDT roles and not just focus on medical and nursing time.

2d. A basic competency framework that services can adapt to their unique requirements should be available to define skills and training requirements.

2e. All Centres must ensure that clinical staff are up to date with key statutory and mandatory training including Basic Life Support for adults and / or children, according to the age ranges of the patients they manage.

Good Practice

Basingstoke CCC

- A physiotherapist-led focus group had resulted in a number of recommendations, and an action plan with clear deadlines for completion.
- A senior nurse provided enhanced peer support, with mentoring and supervision, to nurses across the network.
- A 'baton phone' was held by the out-of-hours on-call consultant covering the service so that users had a single contact number.

Belfast Adults CCC

- There was evidence of extensive in-service training for the team, which was subject to careful annual evaluation.

Birmingham Adults CCC

- Information for healthcare professionals was strong, with a notable 'haemophilia nursing tool' workbook.

Bristol CCC

- A monthly evening clinic, held between 4pm and 7pm, allowed adult patients to attend without missing further education or work.
- Paediatric physiotherapy facilities were co-located with occupational therapy. The adult physiotherapy provision also had access to a hydrotherapy pool in which patients had developed a 'hydrotherapy club'. A physiotherapist rota allowed for reliable cover at times when the dedicated haemophilia physiotherapist was not on site, and had generated a network of 'general physiotherapists' with a good understanding of haemophilia joint problems.

Canterbury CCC

- The physiotherapy team offered point of care ultrasound joint assessments in clinic and ran a clinic jointly with the podiatry team at which patients were proactively seen even if there were no symptomatic problems.
- Extended clinic appointment times, attended by the nurse specialist, alternated with consultant appointments.
- There was an excellent Band 6 development programme for nurses, which was helpful in recruiting more junior nurses and training them up as longer-term team members.

Cardiff CCC

- A detailed staff training matrix was in place.
- Physiotherapists met and treated teenagers and young people in their local gym.

Edinburgh CCC

- A printed clinical audit proforma accompanied each patient to their clinic appointment; this was returned to the administrative & clerical team who submitted data centrally to inform regular assessments of the Centre's key performance indicators.

Glasgow Childrens CCC

- There was a particular focus on orientating and supporting new staff; excellent and detailed induction material.
- The training matrix in place included all team members and identified competences and training each needed for their role.

Great Ormond Street CCC

- The team reviewed affected new-borns immediately, if clinically needed, and otherwise for their heel prick test at approximately 6 days. The babies then attended again for their first immunisations, and one of the nurses undertook a home visit to administer the second immunisation. By the age of 12 weeks therefore, there had already been a good deal of contact and communication with the child and their family.

Guy's and St Thomas' CCC

- A psychologist worked particularly with parents of teenage children over the transition period.

Imperial HC

- A haematologist in training carried a dedicated 'bleep' for the service at all times, in rotation, facilitating access to the clinical team, and supporting continuity. Time spent in this role was also a valuable training opportunity.

Leeds CCC

- A Monday morning handover conference call included all the four consultants on the network-wide on-call rota, nurses, and biomedical scientists, to receive updates about activity over the weekend and to discuss issues and planned patient procedures for the coming week.

Liverpool Adults CCC

- Separate on-call rotas for malignant and non-malignant medical staff ensured that at all times patients had access out of hours to staff who were competent to provide advice and treatment for patients with bleeding disorders.
- The registrar training was comprehensive, with doctors having two blocks of training within the Centre, enabling them to gain a broader and more in-depth understanding of bleeding disorders.
- The team reviewed and responded regularly to Haemtrack and there was a formal weekly review of the data by the team, which ensured that all patient entries were reviewed and responded to in a timely manner.

Manchester Adults CCC

- Specialist haemostasis and thrombosis consultant cover was available out of hours, at all times.

Nottingham CCC

- A locally adapted version of the national haemophilia nurses' competencies template was in use.

Oxford CCC

- There was written induction information and practical teaching for specialist registrars when they joined the team. They did not undertake on-call duties for the first month of their attachment, to ensure they were sufficiently knowledgeable to manage out-of-hours calls.
- Physiotherapist-led exercise classes were held, including a multi-condition group for children and a core/balance class for adults.

Royal Free CCC

- The CNS was on site, if needed, to triage, review and treat patients directly, for four hours on Saturdays and Sundays.

Royal London CCC

- A large number of patients were on pharmacokinetic dosing, ensuring optimal factor levels while allowing for cost savings on some patients who needed less frequent dosing.

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300 Standards: Support Services

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-301	Support Services	35	2	0	95%
HP-302	Emergency Department – staff competences *	28	6	3*	82%
HP-303	Laboratory Service	36	1	0	97%
HP-304	Specialist services	37	0	0	100%

Note:

*Great Ormond Street did not have an ED and for two other Centres (Lewisham and Canterbury) it was not possible to assess the ED as for one Centre, the ED was at another site and for the other the ED was too busy on the day of the review.

Summary

Most Centres had the necessary access to the other relevant specialist and support services required to provide holistic care for patients.

All but one Centre had access to a UKAS accredited laboratory service providing an appropriate range of tests and assays to support clinical decision making and intervention.

1. This set of standards focus on how accessible support services, and colleagues in other specialties, were to the haemophilia team in order to address patients' needs and provide holistic care. Overall, compliance was high.
2. Thirty five Centres had adequate access to support services (including play support, pharmacy, dietetics, occupational therapy and orthotics) and all had access to relevant specialist services (including obstetrics, dental care, HIV services, hepatology etc.).
3. Only one Centre was unable to comply with Quality Standard HP-303: their laboratory was UKAS accredited at the time of the peer review visit. However, UKAS accreditation had been withdrawn for reasons that did not impact directly on the care of patients with bleeding disorders.
4. Quality Standard HP-302 focuses on the competency of ED staff to treat / refer patients arriving in the ED with an acute presentation. Assessment of compliance for this standard was based on speaking to ED staff, evidence that the haemophilia team were providing regular education to ED staff as part of a structured programme, availability of appropriate written guidelines and listening to patients about their experience.

   Patient experience of the ED was very variable, but many reported that they 'did not feel listened to' and there were reports of delays in being seen in a timely manner, failure of ED staff to understand their bleeding disorder and staff ignoring requests to contact appropriate haematology colleagues for onward referral at times when patients felt that this was necessary. This was despite the efforts, by most Centre teams, to provide regular training and awareness sessions in treating bleeding disorders.

Recommendations

3a. Continued efforts are required in all Centres in order to ensure that ED staff have an understanding of the immediate management of patients presenting with bleeding disorders know who to refer to in a timely manner and respect the fact that patients with long-term conditions have considerable knowledge and expertise.

Good Practice

Basingstoke CCC

- There was a clearly visible 'red box' in the ED and other clinical areas, containing laminated copies of the pathways, contact details, full clinical guidelines and guidance on reconstituting and giving concentrates.

Birmingham Children's CCC

- Parents had letters to give to ambulance staff in the event of an emergency, outlining the child's condition and management.

Bristol CCC

- Girls with bleeding disorders could be seen in a paediatric gynaecology clinic.

Cardiff CCC

- Adult patients felt confident of receiving prompt and appropriate care when they were seen out of hours in the ED.

Glasgow Adults CCC

- 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.

Glasgow Childrens' CCC

- 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.

Great Ormond Street CCC

- Use of a BloodTrack® system allowed for issue of blood components for children after a single venous sample had been received in the laboratory, without which two separate venous samples are often required.

Newcastle CCC

- The paediatric ED worked well. Staff had access to the Haemophilia Clinical Information System (HCIS) and were clearly well versed in the care pathway. An easily accessible fridge was available for concentrate storage.

Oxford CCC

- Families reported that they were happy with the care they received in the ED and said that staff seemed competent and engaged.

Royal London CCC

- Dental services worked closely with the Centre team, who had educated patients and local community dentists about the procedures that could safely be carried out without the need for concentrate cover. A novel laser diode treatment was in use for reducing gum bleeding, which had led to reduced bed days as well as the need for concentrate for this complication. The dental team had made a significant contribution to developing the service, in terms of support, commitment and enthusiasm.

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400 Standards: Facilities and Equipment

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-402	Facilities and Equipment	29	8	0	78%
HP-499	IT System *	28	8	0	76%

Note:

*Southampton CCC could not be assessed for HP-499 as they did not obtain Caldicott Guardian permission for reviewers to look at patients notes prior to the visit.

Summary

Most Centres had appropriate facilities and equipment for treatment and most had access to an I.T. system that effectively supported delivery of clinical care.

There were some concerns about security of fridges, or their temperature control, at five sites.

1. This set of standards focus on the suitability of the equipment for providing patient care and the IT systems that are available to staff in order for them to deliver integrated care. Overall, compliance was high.
2. In most of the Centres, there were robust I.T. systems in place that supported staff in providing good care. Reviewers saw evidence of systems that supported the effective planning of care and the sharing of records between members of the MDT.
3. Examples of good practice are highlighted below, but increasingly clinicians were able to access Trust systems remotely when on-call, and make entries to patient records specifying their advice, reducing the risk of mis-recording or misunderstanding. In a number of cases they could also access inpatient observations remotely.
4. In the South West and at the Liverpool Adults' CCC, reviewers heard that the ambulance service had the names of all patients who had bleeding disorders, which enabled them to provide timely treatment or convey the patient to the most appropriate ED. Other Centres agreed that they would appreciate this facility in their own area.
5. In many Centres, there was good communication from the ED when a patient had attended in hours and out-of-hours. This was either via an automatic email alert or via a self-generated email from the ED team. In most Centres, there was an alert on the main patient record that a patient had a bleeding disorder and this was immediately visible to clinical colleagues in all specialties. This helped to ensure that appropriate care and treatment, or onward referral to appropriate clinical colleagues, could be made swiftly and reduced the risk of inappropriate interventions.
6. However, some Centres did report difficulties with recent scanning projects for medical records in their organisations which had resulted in legacy records being scanned in an unstructured, non-chronological manner, meaning that access to historic patient information was time consuming. At worst there may be some risk attached to this and at best clinical time was being wasted in searching previous records.
7. In Northern Ireland, the teams benefitted from an integrated IT system that allowed information to be shared between primary and secondary healthcare organisations, and between health and social care.

Recommendations

4a. Consideration should be given to rolling out the ambulance systems that were seen in two Centres enabling ambulance crews to easily identify that a patient had a bleeding disorder.

4b. There should be an alert on the Trust electronic patient record system indicating that the patient has a bleeding disorder.

4c. There should be an automated alert from the ED confirming that a patient with a bleeding disorder has attended the ED. Centres where there is no alert from the ED system should be encouraged to work with their Trust IT teams to ensure that this relatively basic functionality can be implemented.

4d. Centres should ensure that fridges, in which factor concentrates are stored are secure, with access only for appropriate staff, and that temperature monitoring is in place with an alert system that is triggered if there is a variation in the temperature outside the required range.

Good Practice

Basingstoke CCC

- On the IT system, there was a 'red stick man' alert attached to every patient's record, and a 'critical care plan' detailing all key information of diagnosis, usual treatment and specific concentrate to be given at presentation for injury or bleed.
- It was possible, from the Centre, to access records on patients across the network, even if they had been seen in their local hospital at outreach clinics, and not at the Centre.

Belfast Adults CCC

- An electronic patient record system held copy letters, and laboratory and imaging results, and could be accessed by healthcare professionals across Northern Ireland, including those in primary care.

Bradford HC

- An 'alert' had recently become possible, indicating the diagnosis, for immediate consideration if a patient presented acutely.
- It was possible for consultant staff to access the records remotely, when on call from home, and also to record their comments and advice directly onto the system; Clinical observations of in-patients could also be reviewed remotely from the ward.
- There was also an alert for patients who were on clinical trials, so that the research team would be alerted if any attended.

Bristol CCC

- An alert system was in place with the South West Ambulance Service, so that staff were immediately aware of the patient's condition when a patient using the Exeter Centre required emergency care.
- The Centre team were alerted by e-mail whenever an adult or child known to the service presented to the ED or at any facility throughout University Hospitals Bristol.

Canterbury CCC

- The potential difficulties of working across five hospital sites had been imaginatively addressed, and 'Careflow'®, a locally developed IT system, allowed clinical queries and referrals to be made to the team and their electronic responses to be included in a clearly visible trail.
- This system, as well as clinic letters (including care plans) and laboratory results, could be accessed remotely by clinical staff on call out of hours.

Cardiff CCC

- 'Progeny'®, a genetics information and family tree software system, was in use and could generate a worklist to prompt timely testing and counselling for female relatives of patients who were potential carriers.

Coventry HC

- A database developed locally for monitoring factor usage ensured that accurate data were available and enabled the team to manage stock effectively and reduce wastage.

Glasgow Adults CCC

- An immediate alert appeared on screen as soon as a patient's record was opened.
- There was remote access for on-call staff to view letters and results for patients at Glasgow Royal Infirmary and other linked hospitals. Staff could also enter comments remotely to record the advice they gave.

Leicester CCC

- The medical records were in hard copy, and each had a red triangle alert sticker on the front, and a yellow sticker indicating the need to avoid intra-muscular injections, non-steroidal anti-inflammatory drugs, and aspirin. A more detailed alert sheet giving the diagnosis and treatment constituted the front page within the cover.

Lewisham HC

- An alert on the electronic patient record indicated the patient's diagnosis; when opened it gave more detail including a specific plan for immediate management if the patient presented with a bleed or trauma, and who to contact.
- The clinical notes were mainly still in hard copy and these too had a 'front page' alert indicating that the person had a bleeding disorder.

Liverpool Adults CCC

- Remote access was available for all member of the medical team, and access to inpatient observations and NEWS^2 scores.
- An 'in house' SharePoint repository allowed for easier communication across the team.

Nottingham CCC

- Both the systems used in the ED and the main hospital system flashed a front screen 'alert' of the patient's diagnosis as soon as the record was opened, so that it would not be possible to proceed without the clinician acknowledging the diagnosis.
- It was possible for consultants on-call out of hours to access the system remotely, and to input their comments and advice onto the system.

Oxford CCC

- The Cerner® electronic patient record had a 'flag' tag on its front page once a patient's record was opened.
- If any patient attended the ED, the Centre team received an e-mail alert.

Plymouth HC

- There was a thermal monitoring system activated via Wi-Fi for temperatures in the factor storage fridges in the blood bank. If temperatures went out of range, team members were automatically alerted by e-mail and the switchboard was also informed.

Royal London CCC

- 'Progeny®', a software system designed for use in other long-term conditions, had been adapted by one of the clinical nurse specialists for use in patients with bleeding disorders. This allowed linkage of affected family members with specific genetic mutations across a broad family tree and helped to provide appropriate interventions.

Sheffield Adults CCC

- There was an easily visible 'alert' on the electronic patient record system that indicated that patients had a bleeding disorder.
- Consultants on-call could remotely access key records, including clinic letters and pathology and radiology results even for patients in local district general hospitals, which was useful if teams there needed clinical advice or patients were being transferred.

Truro HC

- The general electronic patient record system and the system used in the ED had an alert visible on opening a patient's record, prompting the user to read the care management plan outlining the patient's diagnosis and treatment. When the care management plan was updated, previous versions were clearly stamped indicating they had been 'superseded'.

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500 Standards: Guidelines and Protocols

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-501	Diagnostic guidelines for patients with suspected inherited and acquired bleeding disorders	27	10	0	73%
HP-502	Guidelines: Concentrate use and monitoring	32	5	0	86%
HP-503	Clinical guidelines	25	12	0	68%
HP-504	Emergency Department guidelines *	29	7	1	81%
HP-505	Guidelines on the care of patients requiring surgery	33	4	0	89%
HP-595	Guidelines on transition and preparing for adult life	31	6	0	84%
HP-599	Care of vulnerable people	37	0	0	100%

Note:

*There was no ED at Great Ormond Street so HP-504 was not assessed.

Summary

In general, written guidelines to support diagnosis, clinical care and treatment were good.

However, the level of detail contained in those documents, the ease of finding any specific topic, document control (see also HP-798) and accessibility for clinical staff was highly variable.

All Centres were able to demonstrate procedures in place for the care of vulnerable patients.

1. These standards focus on the guidelines and documentation that should be available to staff in order to reduce variation within clinical teams, and to give guidance to more junior members of the MDT and to staff providing out-of-hours cover.
2. Overall, compliance with this set of standards was high (average 83%). Many Centres used national UKHCDO guidelines and had amended them relevant sections for application locally in their own organisations. Many excellent, comprehensive, user-friendly clinical guidelines were seen. It was clear that some guidelines appeared to have been written or revised just in time for the visit. However, reviewers were satisfied that the guidelines would help to improve the standard of care as long as they became embedded in regular use, and that relevant staff were familiar with their contents.
3. In four Centres, immediate risks were identified in relation to the guidelines that were in place:
    a. In a 'short guide' for use in the ED and in guidelines intended for managing patients at EDs in other local hospitals, 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. If administered, this large dose would lead to serious clinical consequences.
    b. A clinical guideline for the treatment and management of acute joint bleeds did not state that for patients receiving Emicizumab, activated prothrombin complex concentrate (Feiba) should be avoided, because in combination, these agents can lead to thrombotic microangiopathy and venous thrombosis; such patients should instead receive recombinant factor Vlla (NovoSeven).
    c. In a guideline for the administration of factor IX there was no reference to the risk of anaphylaxis due to inhibitor formation or the need for the first twenty doses to be administered in a suitable hospital setting and not at home.

d. In one Centre, the following risks were identified:

   i. In the guideline on the treatment of von Willebrand disease, the dosing instructions for Voncento™ were not clear. This contains both factor VIII and von Willebrand's factor [RiCof]. The guideline needs to be clear about which component is being used for the body weight-related dosage instruction.

   ii. In the guideline on antenatal care, genetic testing and delivery did not include the need to undertake fetal gender testing at 9/40 (nine weeks' gestation). It also suggested undertaking chorionic villus biopsy [CVS] or cordocentesis at 20/40; CVS should be undertaken at approximately 11/40. Additionally, cordocentesis is seldom undertaken for pre-natal diagnosis of these disorders. The same treatment guidance included the use of DDAVP but did not specify that this was only useful in some patients with haemophilia A, but not patients with haemophilia B or other conditions.

4. Localised diagnostic guidelines for staff caring for patients who were suspected of having a bleeding disorder were in place in 27 Centres. In those Centres deemed not to be compliant with this standard, staff were using the UKHCDO guidelines but had not included reference to local organisational practices. Although staff could usually articulate what they would do in practice this had not been documented.

5. Robust, localised, guidelines on the use and monitoring of factor concentrate were in place in 32 of the 37 Centres.

6. The lowest level of compliance for this group of standards was for HP-503, which required clinical guidelines to be in place covering the management of acute bleeding episodes, the management of inhibitors, dental care, musculoskeletal and joint care and HIV and hepatitis care. Compliance in relation to these guidelines was poor, with ten CCCs and two HCs not being compliant with this standard. Issues included lack of localised content, out-of-date guidelines, multiple guidelines or guidelines with insufficient information. Some guidelines were at variance with UKHCDO guidance

7. Although there was high compliance (81%) with the standard related to ED guidelines, Centres needed to ensure that these guidelines were readily available to ED staff and that associated flowcharts were prominently displayed in the ED. The quality of the ED guidelines varied considerably. Issues included the following: a lack of, or limited content; no guidelines at all (seven CCCs); multiple versions in place; and a lack of clarity regarding dosage calculation.

8. Compliance with the need for guidelines for patients requiring surgery was high. In only two CCCs were surgical guidelines felt to be inadequate. There were many good examples of robust guidelines and associated surgical plans that demonstrated positive communication between the haemophilia specialists and surgical teams for patients with bleeding disorders requiring surgery. With few exceptions, patients who met with reviewers also confirmed that their surgery had generally been planned well and they felt confident that there was a robust plan in place for their surgical procedure.

9. Guidance should be in place for transition and preparation for adult life for young people moving from paediatric to adult services. This includes helping young people to take responsibility for their own care, involving young people in planning the transfer of care and giving advice to young people moving away from home to study. Most (31) Centres demonstrated good compliance with this standard; many used the nationally recognised transition programme for long term conditions – 'Ready Steady Go' – and most had Trust-wide transition policies in place.

10. All Centres were able to demonstrate compliance with HP-599 (relating to the care of vulnerable patients) as all Trusts had safeguarding, restraint and Mental Capacity Act / Deprivation of Liberty policies in place.

11. Although there were many good examples of the documents that were in place, these documents were not always easily accessible to staff.

Recommendations

5a. Centres should ensure that current guidelines and other documentation are complete, up to date, explicit about local implementation, and readily accessible to staff to ensure that staff are aware of what they should do and so that safe practice can be maintained.

5b. Many of the guidelines are fairly generic, so there is opportunity for Centres to share guidelines that were identified as good practice.

5c. The UKHCDO should consider establishing a portal on its website, giving access to commended guidelines submitted by Centres willing to share them, for adoption and approval at other Centres.

5d. Guidance to avoid the use of activated prothrombin complex concentrates (aPCC, 'Feiba') in patients with inhibitors who are receiving Emicizumab (as in combination these agents can lead to thrombotic microangiopathy and venous thrombosis), should be circulated by the UKHCDO to all treating centres, with the request that they include this caution in their clinical guidelines, and recommending instead, the use of recombinant factor Vlla (rVlla, 'NovoSeven') for treating a bleeding episode.

Good Practice

Belfast Adults CCC

- A clear, colourful poster guided ED staff in the initial management of patients presenting acutely.

Birmingham Childrens CCC

- Many excellent documents supported the service, including diagnostic guidelines, ED guidelines, and several clinical guidelines, including that on the management of target joints. A *Home delivery alert* was noted to be very useful.
- There was strong Trust-wide practice and guidance for the transition of young people from paediatric to adult services, and for safeguarding.

Cambridge CCC

- The quality of several of the guidelines, including those for transition between paediatric and adult services, emergency care and the surgical pathway was outstanding.

Glasgow Adults CCC

- Many excellent documents supported the service, 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.

Glasgow Children's CCC

- The diagnostic and clinical guidelines were all clear, well written, and adapted for local use.

Hull HC

- The PATTI information system, which included both individual patient care plans and general clinical guidelines, was accessible to all staff and was felt by reviewers to be an excellent resource.

Imperial HC

- Some outstanding written material supported the service, including a comprehensive operational policy and MDT proforma.

Leeds CCC

- Many of the written guidelines were of a very high standard including: *Use of the coagulation screen in adults* for non-specialist colleagues; a pathway for joint surveillance in the at-risk patient; and pre-surgical and antenatal care plans. A clear 'traffic light' coloured document alerted patients and families regarding possible intravenous line infections. Clear and concise surgery proformas were in place.

Leicester CCC

- There were some particularly good clinical guidelines, such as those covering inhibitor testing and immune tolerance. There was a novel and comprehensive integrated care pathway, *Think, Signal, Move*, for use with young people in transition from paediatric to adult services.

Lewisham HC

- Many high quality written materials supported the service, including: the service guide for patients (a generic patient information leaflet outlining how the conditions could affect them and how to manage them); the clinical guideline section about neuraxial anaesthesia (spinal or epidural blocks); and a comprehensive operational policy.

Newcastle CCC

- Some of the documents supporting the service were of a particularly high standard, including a template for extended half-life product[1] switching, a patient contract for the home delivery service, and the operational policy.

Royal Free CCC

- Some of the guidelines and service descriptions written by team members were especially good, including *Assessment and management of musculoskeletal bleeds in patients with inherited bleeding disorders, Physiotherapy service for patients with Inherited Bleeding Disorders*, the ED guideline and pathway, and a comprehensive home treatment policy.

Royal London CCC

- The *Haemophilia Centre Guidelines* for new team members were very useful.

Sheffield Childrens CCC

- A high standard of documentation supported the service, including clear and succinct diagnostic and clinical guidelines, a surgical pathway, and an overall operational policy. Hard copies of the clinical guidelines were kept readily available on the ward for easy access.
- Policies in place guided the systematic recall of children with mild, unconfirmed bleeding issues in their early teens, to establish a diagnosis before transition to adult services, or to discharge if no significant abnormality was found, and the testing of potential carrier female relatives of affected individuals before they reached child-bearing age, with counselling as necessary.

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600 Standards: Service Organisation and Liaison with other services

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-601	Service Organisation	28	9	0	76%
HP-602	Multi-disciplinary team meetings	32	5	0	86%
HP-603	Multi-disciplinary clinics	24	13	0	65%
HP-604	Liaison with other services	15	22	0	41%

Summary

Overall, most Centres could demonstrate strong multi-disciplinary team working within the haemophilia team and also with colleagues in other Trust specialities.

Many Centres had policy documents that described how the service functioned.

MDT meetings were in place in many Centres.

Fewer than half of services had robust arrangements for communication with other services with whom they worked.

1. These standards focus on the organisation of the service and multi-disciplinary working within the haemophilia team and with other services.

2. Most Centres had an operational policy in place that described how the service worked and that included the following: patients having named consultants; arrangements for patients who 'did not attend'[8]; arrangements for transferring patients moving to other Centres; home visits and lone working. The length and detail of these documents varied considerably. Articulating the operation of the service is of great value to existing and new members of staff. There were some examples of good practice that could be readily shared with Centres whose polices were not robust.

3. Multi-disciplinary team within Centres were mostly working extremely well. There was evidence of team meetings taking place regularly with representation from various staff groups. Often there were clear agendas and these meetings were minuted. In those Centres identified as examples of good practice, there were also action plans in place outlining who was responsible for completing actions, and reviewers saw examples of actions and evidence of follow up. Some Centres were recording these MDT discussions in patient notes. In many Centres, however, under provision in one or more staff groups made it impossible for MDT working to be complete. These Centres were not recorded as non-compliant when regular meetings were held with the team members that were in place.

4. In some Centres, there was evidence of joint clinics with other disciplines including orthopaedics, obstetrics, dentistry and hepatology. This ensured that patients were receiving seamless care and were confident because their haematologist or haemophilia nurse were present when their care plan was being discussed with other specialties. However, especially where staffing levels were low, joint clinics were not always felt to be the optimal use of the team's time, and as long as there was good communication between the Centre teams and colleagues, care quality did not suffer.

[8] For children, 'did not attend' does not apply as they rely on others to bring them, so the recognised term is 'was not brought'.

5. HP-604 requires that *'review meetings should be held at least annually with specialist services to consider liaison arrangements and address any problems identified'.* Although communication generally worked well, this was rarely in the form of regular, formal combined meetings with colleagues.

   [Note: It is recommended that this standard is removed in the next iteration of the Quality Standards].

Recommendations

6a. Each Centre should review the adequacy of their operational policy, ensuring it covers the elements of HP-601.

6b. At all Centres, MDT meetings should be minuted and include action logs with the names of individuals who will be responsible for ensuring that the actions are completed. Any decisions reached after discussion should be included in the applicable patient's records.

6c. Clearly documented communication is needed between clinical teams when co-managing patients, and patients should receive copies of this to reassure them that their speciality team is appropriately involved in care planning.

Good Practice

Basingstoke CCC

- The Trust's orthopaedic team specialising in ankle problems held a dedicated weekly clinic 'slot' at the start of the clinic for patients with bleeding disorders so that members of the Centre team could attend with patients when they were seen.

Belfast Childrens CCC

- Urgent samples for processing in the laboratory on the City Hospital site were conveyed by 'pod', and a dedicated porter there facilitated conveying factor concentrates back to Royal Belfast Hospital for Sick Children when needed urgently.

Birmingham Childrens CCC

- Ready support was available from radiology for rapid ultrasound scanning to assess possible joint bleeds.
- Gynaecologists attending from Heartlands hospital offered on-site clinic appointments for teenagers with bleeding disorders.

Birmingham Adults CCC

- The ambulance service held a list of all patients registered at the Centre, with instructions to bring them to the Queen Elizabeth Hospital Birmingham for all but possibly time-critical injuries for which they needed to be taken to a more local ED.

Coventry HC

- Time invested in the development of a network of link nurses in adult clinical areas ensured that when the specialist team members were not available, staff were available who had the required level of clinical knowledge to manage patients appropriately.

Derby HC

- There was very good pre-natal and neonatal services, with a joint obstetric clinic in which carrier women were seen pre-conceptually, and a plan recorded on the 'Lorenzo®' patient record system that was immediately visible when a woman booked for pregnancy care. Genetic counselling was available on site, with a counsellor from the Nottingham CCC offering outreach appointments.
- The 'KITE' team (specialist nurses who care for children and young people with long-term conditions at home), provided valued advice and education, as well as being a link between the family and the hospital MDT.

Glasgow Adults CCC

- 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.

Great Ormond Street CCC

- The management of delivery for pregnant carrier women was carefully planned, with mothers given a 'baby pack' before the birth, including a tube for cord blood to be collected for immediate testing to see if the baby was affected, a dose of vitamin K and a small dose of the relevant factor concentrate.

Guys and St Thomas' CCC

- Transition practice was excellent, with a consultant, nurse specialist and physiotherapist from both the paediatric and the adult teams jointly reviewing a young person from the age of approximately 14 years. The young person continued to attend this combined clinic until the age of approximately 18, when their care was taken over by the adult team.
- There was an innovative approach to teaching teachers and nurses at the schools attended by the children, using 'Skype' sessions, saving travelling time for the professionals while still enabling them to give personal tuition to school staff.

Manchester Childrens CCC

- The guideline for children undergoing surgery, and the surgical management plans, were very good and the team held a 'virtual' clinic weekly to discuss plans for children having any procedures in the forthcoming week.

Manchester Adults CCC

- Haematology midwives supported an excellent joint haematology and obstetric clinic. Women with complex pregnancies had open access to them for support and advice, and they provided a key interface with other hospitals in the region at which the women may have planned deliveries.

Oxford CCC

- There was very good support from other specialist teams. Paediatric interventional radiology was helpful and prompt when requested to insert intravenous access devices and perform urgent ultrasound scans and MSK radiology in undertaking musculo-skeletal ultrasounds for children at the John Radcliffe Hospital. In the adult service, the management of synovitis was helped by a named specialist radiologist reporting all the MR joint scans, and there was a monthly joint clinic with rheumatology at which joint injections could be given if appropriate. Radioactive synovectomy was also available.

Sheffield Adults CCC

- Patients undergoing surgery at the Northern General Hospital were jointly managed with the Centre team peri-operatively and then once stable from a surgical viewpoint, were transferred to the Royal Hallamshire Hospital for the remainder of their inpatient stay under the direct care of the bleeding disorders team.

Southampton CCC

- There was exemplary joint working with a named obstetrician. Women with bleeding disorders or who were at risk of having an affected infant, and who were planning pregnancy or were already pregnant, were seen at shared fortnightly clinics, with careful communication with all other members of the extended team as needed. The named obstetrician was also the lead for maternal medicine and chaired the regional maternal medicine committee. Obstetric colleagues often contacted him by email for clinical advice. A specialist colleague at Southampton worked with him and provided cover.

St Georges HC

- Surgical management of patients was good, with appropriate clear guidelines and care plans. Patients reported positive experiences when they had required surgery.

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700 Standards: Governance

Ref	Quality Standard	Number met	Number not met	N/A	% met
HP-701	Data collection	32	5	0	86%
HP-702	Audit	11	26	0	30%
HP-706	Research	31	6	0	84%
HP-798	Multi-disciplinary review and learning	29	8	0	78%
HP-799	Document control	13	24	0	35%

Summary

Most Centres were able to demonstrate that they had clinical governance arrangements in place for reviewing service performance and quality.

Additional work is needed in many Centres to ensure that key clinical activities are regularly audited.

Documents should comply with Trust documentation control arrangements to provide assurance that staff are accessing the most up to date policy and guidance.

1. These standards focus on the clinical governance arrangements that should be in place to ensure that qualitative and quantitative information is collected and reviewed. This will help to demonstrate the quality of the service being provided and to provide evidence that appropriate action was taken in response to any identified concerns, including those raised by any incidents or complaints.

2. Most Centres (32) had robust arrangements in place for collecting and submitting data to the National Haemophilia Database, Haemtrack and the UKHCDO haemophilia dashboard. Of the Centres who were not compliant with this standard, three were CCCs and two were HCs.

   [Note: at the time of the review, Haemtrack was not in place in Northern Ireland (explaining the non-compliance of two CCCs). In addition, Centres in Wales, Scotland and Northern Ireland were not required to make submissions to the National Haemophilia Dashboard, but compliance was given as 'Yes', where the other elements of the standard were in place].

   However, a general concern was highlighted that not all CCC's could give accurate patient numbers and activity data for their own Centre, and most did not hold data on the patients at their linked HC's or DGH's. Data sharing across networks was variable and often absent. A CCC therefore sometimes had no oversight of key outcomes for patients at its linked Centres, or direct activity measures such as factor usage.

3. HP-702 requires evidence of a rolling programme of audit including at least the following: the practical application of clinical guidelines (HP-503); emergency and out-of-hours care; the initiation of prophylaxis in children; inhibitor surveillance and Immune Tolerance Induction (ITI); clinical reviews including joint scores (HP-103 & HP-104) and concentrate use and wastage. This information is important for benchmarking and identifying areas for improvement and is useful for local and national commissioners. Overall, compliance with this quality standard was poor, with only three HCs and eight CCCs (30%) being compliant. Good governance activity in general was seen in a number of the small HCs whereas in some of the larger, well-staffed Centres recent audit activity was low.

4. Most Centres (84%) had active research programmes in place. Of the six Centres who did not meet the requirements of this standard, three were HC's. It is important that these Centres are part of the research activity and trials provided by their linked CCCs in order to ensure consistency of access to new treatment options.

In most of the large CCCs, the research and clinical trial activity was significant and, in almost half of the CCCs and one HC, the trials that they were leading were of international importance, which was reflected in the Achievements sections of their individual reports. In a small number of services, the savings that had been generated from research activity had been reinvested to employ additional, much needed, staff. In Cardiff reviewers heard that the development of the new network had been primarily funded as a result of savings generated from research. This was an excellent example of good practice.

In most Centres undertaking active research, there were identified research nurses in the team, who could sometimes support clinical work covering colleagues' absence, as well as managing research activity.

5. HP-798 requires Centres to have multi-disciplinary arrangements in place for reviewing and implementing learning from the following: feedback (including complaints, outcomes, incidents and 'near misses'); morbidity and mortality; the haemophilia dashboard; UKHCDO annual report benchmarking information on concentrate use; ongoing reviews of service quality, safety and efficiency and published scientific research and guidance.

   Compliance with this standard should provide assurance to the specialist team, the wider Trust, the network and commissioners that the service is reflective, learns from positive feedback as well as errors and is responsive and willing to change and adapt as a result of the qualitative and quantitative information received. Regular opportunities for the MDT to share and learn from feedback are essential to maintaining quality of care and being able to demonstrate this to key stakeholders. Most Centres (29) were able to demonstrate compliance with this standard. In those Centres where compliance was not achieved, this was often linked to a significant lack of staffing, so that staff were focussing on their clinical roles and did not have sufficient time to focus on governance and service development activities.

6. In many Centres the outcomes of MDT discussions were also included in the patients notes, where appropriate. However, although there were many examples of good practice, meetings were sometimes not fully documented and there was often no evidence of who was responsible for the actions identified, or of any system for following-up and ensuring completion of the actions.

   In some Centres, reviewers also saw evidence of review and learning across the networks (see the '800 Standards: Network' section later in this report).

7. Good governance requires that documents include authorship and review details so that it is clear to all staff what the latest version of the document is and who they should refer to if they are unclear. Compliance with standard HP-799 (Document control) was poor. Only 35% of Centres were judged overall to have effective document control in place. For most, but not all Centres, document control for Trust wide policies provided as evidence (e.g. safeguarding, MCA / DOLs, transition) was generally good. However, this was not the case for local guidelines, SOPs or patient information, where often there was no note of authorship, no date on which the document had been developed or approved, no version number, and no date when it was due for review. In addition, in some Centres there were multiple versions of the same document included as evidence.

Recommendations

7a. Centres need to prioritise service quality reviews and audits to help them understand and evidence the quality of the service that is being delivered and identify areas for improvement.

7b. Any planned changes to patient care arising from MDT discussions should be documented in the patients' medical records.

7c. In those Centres in which review and learning meetings are taking place, the Centres should ensure that these meetings are documented and that action plans include details of those responsible for taking actions forward.

7d. In Centres where review and learning is not embedded, action is needed to ensure that this important activity is implemented and embedded in the routine activity of the team.

7e. Work is required in the majority of Centres to ensure that Trust policy on document control is implemented for all guideline and policy documents supporting the service. If documents include authorship and review details, it is clear to all staff what the latest version of the document is and who they should refer to if they are unclear, reducing the risk of errors.

7f. Patients in all Centres should be made aware of the research studies for which they would be eligible and offered entry to them.

7g. Document control was either missing or not robust in about two-thirds of Centres. Poor document control can lead to the wrong version of a procedure being used or changed. Robust document control procedures underpin high quality policies and procedures.

Good Practice

Alder Hey Children's CCC

- An audit of factor dispensed against factor actually used, undertaken as part of a CQUIN, was noted as this is an issue that some Centres do not scrutinise.

Basingstoke CCC

- A rolling programme of audit was in place, with responsible team members named for each audit.

Canterbury CCC

- There was exemplary governance arrangements, with a comprehensive and active audit programme and a well-attended and minuted monthly 'Haemophilia business, clinical governance and audit' meeting. Every opportunity was being taken for review and learning, and for reflection on and improvement of the service.

Coventry HC

- Governance arrangements were excellent, with a comprehensive and active audit programme and well-attended MDT meetings, that produced a detailed action log including the names of those assigned to specific actions. Opportunities were taken for review and learning, and for reflection on and improvement of the service.

Derby HC

- Audits of service delivery and outcomes had recently been undertaken, covering most of the important aspects of care.
- Document control was good, with guidelines and operating procedures recording authorship, date of implementation and review date.

Nottingham CCC

- The clinical governance activities were well developed, with a comprehensive audit programme focusing on all the most important aspects of diagnosis and treatment.
- MDT meetings, and other meetings at which review and learning took place, were fully minuted. Individual patient discussions at MDT meetings were recorded on a proforma and scanned into the permanent electronic health record.

Oxford CCC

- The clinical governance activities were comprehensive, with minuted meetings covering mortality and morbidity case reviews and review and learning from incidents. There was an active audit programme in place, with evidence of changes made as a result of findings.

Sheffield Adults CCC

- MDT working was exemplary, with good attendance at weekly meetings and formal minutes available on the hospital 'shared drive'. MDT discussion outcomes were also included in individual patient record files.

Sheffield Childrens CCC

- There was a comprehensive rolling audit programme, with many audits having been completed, presented, and actioned. There were specific plans for audits in the forthcoming year.

Truro HC

- There were strong governance processes within the wider haematology department, with quarterly meetings, including mortality reviews and discussion of incidents and complaints, and the possibility of extra meetings every month if more urgent issues arose. The haemophilia team participated fully in these meetings.

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Commissioning and Network Arrangements

In England, services for people with inherited and acquired bleeding disorders were commissioned by NHS England (NHSE), as specialised services. This was part of the 'Blood and Infection' national programme of care. The 2013 service specifications cover the elements of care that were expected to be provided by the CCCs. This includes care for patients who live some distance from a CCC via a managed clinical network that must include at least one CCC. Networks should include at least one CCC together with their linked HC's with which they are linked to provide support and joint working.

In Wales, the Cardiff CCC was commissioned by the Welsh Health Specialised Services Committee. In Scotland, IABD services were commissioned through the National Services Division (NSD). Coagulation and factor concentrates were also purchased by the NDS through a risk sharing agreement. In Northern Ireland, the Health and Social Care Board commissioned specialist services in line with the NHSE framework.

For the purposes of this programme, Centres in England, Wales, Scotland and Northern Ireland were assessed against the same Quality Standards in regard to network functioning and commissioner engagement.

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800 Standards: Network

Ref	Quality Standard	Number met	Number not met	N/A	% met
HY-199	Involving patients and carers	15	22	0	41%
HY-203	Inherited and acquired bleeding disorders network leads	8	29	0	22%
HY-204	Education and training	13	24	0	35%
HY-503	Guidelines	9	28	0	24%
HY-701	Ongoing monitoring	14	23	0	38%
HY-702	Audit	2	35	0	5%
HY-703	Research	9	28	0	24%
HY-798	Network review and learning	11	26	0	30%

[Note: Most HCs completed the network standards themselves. However, three Centres: Derby, Bradford and Lewisham did not and for these Centres, the compliances used were those of their CCC]

Summary

The extent to which networks were functioning was extremely variable and overall, compliance with these standards was poor.

Considerable effort had gone into embedding the networks in some places, usually under the leadership of enthusiastic clinicians and in only a few places with clear support from the commissioners.

In all areas, the CCC teams offered clinical advice and guidance to colleagues at smaller linked Centres as required in and out-of-hours. However, this was often the only aspect of networking that was in place.

A number of CCC leads stated that they were unaware that they were supposed to work jointly with their linked Centres in any other ways.

Only one Centre was fully compliant with the network standards.

1. Networks are expected to have nominated leads for each professional group (consultant, specialist nurse, physiotherapist, psychologist and manager), with these leads being responsible for: a programme of education and training; sharing diagnostic and clinical guidelines; monitoring data concentrate and use and bleed rates and undertaking shared audits. The leads should meet at least annually to review audits and action plans, to hold review and learning discussions – looking at incidents, complaints, and mortality and morbidity reports – and to discuss service development. Feedback from patients across the network should be discussed and patients from all Centres should be invited to take part in appropriate research studies.
2. Provision of outreach clinics, in which CCC staff travel to linked hospitals to undertake clinics, for the convenience of patients is not an explicit expectation of networking but such clinics are greatly appreciated by patients and are an educational opportunity for the local teams. These outreach clinics were being offered by only six CCCs: Basingstoke, Birmingham Adults, Bristol Childrens, Belfast Adults, Belfast Children's and Guy's and St Thomas'.
3. Effective, functioning, network arrangements were in place in only three networks: the Southern Haemophilia Network (based around the North Hampshire CCC in Basingstoke); the North West Yorkshire Haemophilia Network (managed from the Leeds CCC) and the Scottish Inherited Bleeding Disorders Network.
    a. The Southern Haemophilia Network was formally commissioned with Service Level Agreements in place between the four main Trusts. There were shared guidelines, weekly MDTs via telephone and video conference, monthly governance meetings, data sharing and the involvement of patients across the network – both in giving

feedback and being offered entry into research studies. The network met four times a year and agendas included educational sessions and service reviews. Network audits were planned. Flexibility of staff working across all of the hospital sites, to allow cover for absences, was well developed.

b. The North West Yorkshire Haemophilia Network was a formal, clinically-led operational network between the Leeds, Bradford and York Centres. It provided 24/7 on-call consultant and specialist laboratory services on a network-wide basis. There were monthly network meetings, alternating between a clinical MDT meeting and a business meeting. The latter was co-chaired by the clinical network lead and a commissioner from the regional specialised commissioning team. There was a multi-professional education programme and strong patient and public engagement.

c. The Scottish Inherited Bleeding Disorders Network (SIBDN) was established in 2016. There were three active workstreams in place: stakeholder engagement and communication; best practice, policies and protocols and quality improvement, audit and data. The network had successfully published national guidelines, produced a comprehensive patient information booklet and undertaken Scotland-wide auditing of data against a set of Key Performance Indicators. It also held regular education events for staff. Commissioners regularly attended the network meetings and there was a full annual report and work plan in place. Members of the Glasgow CCC's had made significant contributions to the activities of the SIBDN.

4. Partially functioning networks were operating in several other CCCs. In the majority, those meetings that had been held had mainly focussed on factor usage and wastage, and sometimes on staffing issues. They rarely included other governance issues, audits or education programmes. These networks were seen at Birmingham Adults' and Children's CCCs, where there was progress being made towards a multi-professional programme board; at Bristol Childrens, where guidelines were shared and there were developed plans for education and business meetings and in the East Midlands (Nottingham, Leicester, Derby and Lincoln) where there was some shared data analysis, case discussions and educational events. There was an informal North East and Cumbria network, centred on the Newcastle CCC, where there was some network-wide audit and plans for formal, regular, meetings.

5. In Cardiff, a full network was emerging with the support of the Welsh Health Specialised Services Committee. Progress with this had been possible because of the considerable savings made on concentrate use, due to active participation in research studies.

6. In London, there were two explicitly commissioned networks. In the north, Great Ormond Street was the hub for paediatric services and the Royal Free Hospital was the hub for the adult network. This linked with the CCC at Barts Health and the HC at Imperial College. In south London, the lead CCC for the network was Guy's and St Thomas' Hospital which linked with the HCs at St Georges Hospital and Lewisham Hospital. Unlike the networks described above, which were mostly quite recently established and were in the process of embedding practice, the London networks appeared in some regards to be declining. Four or five years ago there had been regular network meetings and activities with some useful outputs being described. However, in recent years very few meetings had taken place and when they had occurred the focus had mainly been on concentrate usage and wastage.

7. Although a few CCCs had been willing to support any nearby HCs and DGHs with clinical advice, they were unaware of the expectations that they were key to network developments and therefore none of the other elements of network functioning were in place. These included Sheffield and Cambridge.

8. Some CCCs, which included the Belfast Adults and Children's, Canterbury, Manchester Adults' and Children's and Oxford Centres did not have linked HCs and therefore indicated that they did not have a network. However, at these and other Centres, there were informal links with DGHs to which IABD patients could present acutely with a trauma or bleed. In these cases, some CCCs had identified 'link' haematologists and paediatricians at the local hospitals. It was agreed that this was extremely valuable and that there should be further focus on this joint working to provide support and education for non-specialist colleagues and to improve the quality of care for patients. Indeed, within the London networks, many senior clinicians felt that their time would be more usefully spent developing these support systems, rather than meeting with other highly specialist colleagues in the formally linked Centres.

9. Twelve of the Centres did not meet any of the network standards at all. Twenty-nine Centres (22%) did not have an identified network lead for their network and only 30% participated in any shared education and learning events on a network basis. HY-503 requires CCCs to share their guidelines with HCs and this was happening in only eight of the Centres. There was no shared audit work being undertaken and 28 did not have any network research policies. Only nine Centres had regular network learning and review meetings.

Recommendations

8a. Commissioners should be explicit about the network arrangements they expect to be in place, and to give adequate resources to the CCC teams to lead and develop their networks.

8b. Each network needs to have nominated leads for each professional group – consultant, nurse specialist, physiotherapist, psychologist and manager.

8c. Networks should meet at least once a year to discuss service developments, to study data from each Centre, to review audits and action plans, and to have review and learning discussions arising from any complaints or incidents.

8d. Network-wide educational sessions should be offered.

8e. Feedback from patients treated at all Centres should be collated and discussed.

8f. Specialist teams should review job plans in order to offer some outreach clinics wherever possible as part of the network arrangements, to reduce inconvenience and travelling time for patients and families, and to offer educational opportunities for staff at smaller Centres.

8g. Teams should also focus on strengthening informal links with colleagues at the DGHs that their patients might attend in an emergency.

Network standards compliance by Centre

Network								
Ref Number	HY-199	HY-203	HY-204	HY-503	HY-701	HY-702	HY-703	HY-798
Quality Standards	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	**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	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HP-203.	**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)	**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	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QS HP-702	**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.	**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
1	N	N	N	N	N	N	N	N
2	N	N	N	N	N	N	N	N
3	N	Y	N	N	N	N	N	N
4	Y	Y	N	N	N	N	N	N
5	Y	N	Y	N	Y	N	N	Y
6	N	N	Y	N	Y	N	N	N
7	Y	Y	N	Y	Y	N	Y	N
8	N	N	N	N	N	N	N	N
9	N	N	Y	Y	Y	N	N	Y
10	Y	Y	N	N	N	N	N	N
11	N	N	N	N	N	N	N	N
12	N	N	N	N	N	N	N	N
13	N	N	N	N	N	N	Y	N
14	Y	N	Y	N	Y	N	N	Y
15	Y	N	Y	N	Y	N	N	Y
16	N	N	Y	Y	Y	N	N	N
17	Y	Y	Y	Y	Y	Y	Y	Y
18	Y	N	N	N	N	N	N	N
19	N	N	N	N	N	N	N	N
20	N	N	N	N	N	N	N	N
21	Y	N	Y	N	N	N	N	Y
22	N	N	N	N	N	N	N	N
23	N	N	N	N	N	N	N	N
24	N	N	Y	N	Y	N	N	Y
25	N	N	Y	Y	Y	N	N	Y
26	Y	Y	Y	Y	Y	Y	Y	N
27	Y	N	N	N	N	N	N	N
28	N	N	N	N	N	N	N	N
29	N	N	N	N	Y	N	N	N
30	Y	N	N	N	Y	N	Y	N
31	Y	Y	Y	Y	Y	N	Y	Y
32	N	Y	N	N	N	N	N	Y
33	Y	N	N	N	N	N	N	N
34	N	N	N	Y	N	N	Y	N
35	N	N	N	N	N	N	Y	N
36	Y	N	Y	N	N	N	N	Y
37	N	N	N	Y	N	N	Y	N
% Compliance	41	22	35	24	38	5	24	30

[Note: One CCC did not complete any of the network or commissioning standards and the judgement on compliance was therefore based on what was seen and heard on the day of the review. For all other CCCs, compliances were based on the evidence presented on the day of the review. Although some HCs did complete these standards, some did not, and for those Centres the compliances included in their individual reports and in the table above are replicated from the compliances of their hub CCC].

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900 Standards: Commissioning

Ref	Quality Standard	Number met	Number not met	N/A	% met
HZ-601	Commissioning of services	18	19	0	49%
HZ-701	Clinical quality review meetings	9	28	0	24%
HZ-798	Network review and learning	9	28	0	24%

[Note: One Centre (Imperial) did not complete the Commissioning standards. The compliances for its CCC (Royal Free) have therefore been used.]

Summary

The extent to which commissioners were engaged with clinical and service leads varied enormously. In a few areas they had close working partnerships with lead clinicians, had agreed a detailed configuration of services, had taken part in service quality reviews and had attended and/or hosted network meetings. However, some Centre directors who had been in post for many years had never met any members of the specialised commissioning team and were unaware of who they were.

While network functioning was certainly at its best where there was committed commissioner involvement, several sites were offering a very high quality of service and striving to establish networks without any commissioner support.

1. These standards outline the expected requirements for commissioning arrangements for bleeding disorder services across the UK.
2. Engagement with commissioners was particularly strong in the south central region, north west Yorkshire and Scotland, where the most effective networks were established. The Belfast Adults' Centre director also worked closely with the commissioner. Birmingham network meetings were hosted by the commissioner, whereas the East Midlands network meetings were clinically led, with no commissioner input. For London and the North West, reviewers heard that previously supportive and productive joint working with commissioners had decreased over recent years.
3. These three standards outline the expected requirements for commissioning arrangements for bleeding disorders across the UK. They require a specification for the clinical network that provides clarity on the working arrangements and referral pathways between CCCs and HCs in the network, as well as evidence that commissioners are regularly reviewing the quality of services being provided including qualitative and quantitative information and learning from incidents.
4. Only 44% of Centres could provide evidence that there was an agreement in place that described the relationships between the Centres in the network and the referral pathways for adult and paediatric patients. However, even where there were written agreements in place it should be noted that many had not been reviewed for several years and were as much as ten years old.
5. Only eight Centres (22%) could provide evidence that they met regularly with their commissioner colleagues to discuss service provision and review quality and other KPIs. These Centres were in the Southern, Scottish and North West Yorkshire networks – which have already been highlighted as the only examples where full network arrangements were in place.

Commissioning standards compliance by Centre

Ref Number	HZ-601	HZ-701	HZ-798
Quality Standards	**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	**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	**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.
1	N	N	N
2	N	N	N
3	N	N	N
4	Y	N	N
5	Y	Y	Y
6	N	N	N
7	Y	Y	Y
8	N	N	N
9	N	N	N
10	Y	N	N
11	N	N	N
12	N	N	N
13	N	N	N
14	Y	Y	Y
15	Y	Y	Y
16	Y	N	N
17	Y	N	N
18	Y	N	N
19	N	N	N
20	N	N	N
21	Y	Y	Y
22	N	Y	Y
23	N	N	N
24	N	N	N
25	N	N	N
26	Y	Y	Y
27	Y	N	N
28	N	N	N
29	N	N	N
30	N	N	N
31	Y	Y	Y
32	Y	N	N
33	Y	N	N
34	Y	N	N
35	N	N	N
36	Y	Y	Y
37	Y	N	N
% Compliance	49	24	24

Recommendations

9a. Urgent discussions are required at the Specialised Blood Disorders Clinical Reference Group meeting, and between other key stakeholders, regarding the substantial variation in commissioner engagement, the extent and type of network functioning and inequalities in service quality across the UK for children and adults with IABD.

9b. Commissioners need to be explicit about the network arrangements they expect to be in place, and to give adequate resources to the CCC teams to lead and develop their networks.

9c. Commissioners should regularly review the quality of the service provided at each Centre, as evidenced by data submitted regarding factor use and bleed frequency, and clinical audit findings.

9d. Commissioners should attend network meetings at least annually and take part in review and learning discussions.

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Other Recommendations

1. UKHCDO should ensure that there are mechanisms in place for sharing the Good Practice and learning identified during this programme, to help ensure that real quality improvement can result from the review process.
2. UKHCDO should consider a further review of Centres in two to three years, in order to measure whether recommendations for service quality improvement have been implemented.

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APPENDIX 1 Steering Group Members

Name	Position	Organisation
Dr Helen Aiston	Highly Specialist Clinical Psychologist	Hampshire Hospitals NHS Foundation Trust
Dr Julia Anderson	Consultant Haematologist	Edinburgh Haemophilia Care Centre NHS Lothian
Sarah Bowman	Haemophilia Social Worker	Sheffield Teaching Hospitals NHS Foundation Trust
Sarah Broomhead	Assistant Director	WMQRS
Liz Carroll	Chief Executive	The Haemophilia Society
Dr Elizabeth Chalmers	Consultant Paediatric Haematologist	NHS Greater Glasgow and Clyde
Jane Eminson	Director	WMQRS
Dr Gillian Evans	Consultant Haematologist Director of Kent Haemophilia and Thrombosis Centre	East Kent Hospitals University Foundation Trust
Dr John Hanley	Consultant Haematologist UKHCDO Peer Review Group Chair	The Newcastle upon Tyne Hospitals NHS Foundation Trust
Cathy Harrison	Haemophilia & Thrombosis CNS/ANP	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Lishel Horn	Consultant Haematologist Director of Leeds Haemophilia Centre (Adults)	Leeds Teaching Hospitals NHS Trust
Dr Kate Khair	Haemophilia Nurse Consultant	Great Ormond Street Hospital for Children NHS Foundation Trust
Graham Knight	Patient representative	
Dr Ri Liesner	UKHCDO Chair, Consultant in Paediatric Haemostasis and Thrombosis	Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Rhona MacLean	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Tim Nokes	Consultant Haematologist	Plymouth Hospitals NHS Trust
Anna Wells	Clinical Specialist Physiotherapist Chair Haemophilia Chartered Physiotherapists Association (HCPA)	Hampshire Hospitals NHS Foundation Trust
Lianne Willey	Patient representative	
Dr Anne Yardumian	Consultant Haematologist	North Middlesex University Hospital NHS Trust

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APPENDIX 2 Summary of Services Reviewed

Key:

CCC – Comprehensive Care Centre
HC – Haemophilia Centre
A - Adults
P - Paediatrics

Centre	Trust	Review Date	Adult or Paediatric Service
Hull HC	Hull and East Yorkshire Hospitals NHS Trust	20/11/18	A&P
Great Ormond Street CCC	Great Ormond Street Hospital for Children NHS Foundation Trust	12/12/18	P
Royal London CCC	Barts Health NHS Trust	14/12/18	A&P
Royal Free CCC	Royal Free London NHS Foundation Trust	17/01/19	A
Edinburgh CCC	Royal Infirmary of Edinburgh	22/01/19	A&P
Newcastle CCC	The Newcastle upon Tyne Hospitals NHS Foundation Trust	27/02/19	A&P
Basingstoke CCC	Hampshire Hospitals NHS Foundation Trust	07/03/19	A&P
Bristol CCC	University Hospitals Bristol NHS Foundation Trust	21/03/19	A&P
Derby HC	University Hospitals of Derby and Burton NHS Foundation Trust	26/03/19	A&P
Imperial HC	Imperial College Healthcare NHS Trust	08/04/19	A
Sheffield Adults CCC	Sheffield Teaching Hospitals NHS Foundation Trust	02/05/19	A
Sheffield Childrens CCC	Sheffield Children's NHS Foundation Trust	03/05/19	P
Cambridge CCC	Cambridge University Hospitals NHS Foundation Trust	09/05/19	A&P
Glasgow Childrens CCC	Royal Hospital for Children, Glasgow	15/05/19	P
Glasgow Adults CCC	Glasgow Royal Infirmary	16/05/19	A
Birmingham Childrens CCC	Birmingham Women's and Children's NHS Foundation Trust	10/06/19	P
Canterbury CCC	East Kent Hospitals University NHS Foundation Trust	13/06/19	A&P
Cardiff CCC	Cardiff and Vale Health Board	17/06/19	A&P
Birmingham Adults CCC	University Hospitals Birmingham, NHS Foundation Trust	02/07/19	A
Truro HC	Royal Cornwall Hospitals NHS Trust	16/07/19	A&P
Leeds CCC	Leeds Teaching Hospitals NHS Trust	02/09/19 & 03/09/19	A&P
Southampton CCC	University Hospital Southampton NHS Foundation Trust	09/09/19	A&P
Plymouth HC	University Hospitals Plymouth NHS Trust	12/12/19	A&P
Leicester CCC	University Hospitals of Leicester NHS Trust	01/10/19	A&P
Nottingham CCC	Nottingham University Hospitals NHS Trust	02/10/19	A&P
Oxford CCC	Oxford University Hospitals NHS Foundation Trust	09/10/19	A&P
Belfast Children's CCC	Belfast Health and Social Care Trust	17/10/19	P
Belfast Adults' CCC	Belfast Health and Social Care Trust	18/10/19	A
Coventry HC	University Hospitals Coventry and Warwickshire NHS Trust	05/11/19	A&P

Manchester Children's CCC	Manchester University NHS Foundation Trust	21/11/19	P
Manchester Adults' CCC	Manchester University NHS Foundation Trust	22/1//19	A
Liverpool Adults' CCC	Liverpool University Hospitals NHS Foundation Trust	26/11/19	A
Liverpool Children's CCC	Alder Hey Children's NHS Foundation Trust	27/11/19	P
Guy's and St Thomas' CCC	Guy's and St Thomas' NHS Foundation Trust	04/12/19	A&P
St George's HC	St George's University Hospitals NHS Foundation Trust	18/12/19	A&P
Bradford HC	Bradford Teaching Hospitals NHS Foundation Trust	22/01/20	A&P
Lewisham HC	Lewisham and Greenwich NHS Trust	28/01/20	A

Note: If a CCC was on different sites or was part of different Trusts, one day of review time was spent at each. For other Centres providing adult and paediatric care on the same site and as part of the same Trust, the review was completed in one day.

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APPENDIX 3 Glossary of Terms and Abbreviations

Clinical Reference Group (CRG)	Inherited bleeding disorders are one of the groups of conditions commissioned by the NHS as a 'specialised service'. The Specialised Blood Disorders Clinical Reference Group [CRG] is the group which brings together clinical expertise and advice with the views of patients and carers, to plan service development and delivery.
Concern	Concerns relate to the standards or prerequisites for their achievement. A significant absence that impacts on delivery or outcomes will lead to a concern being identified by the review team. Some concerns may be categorised as 'serious'.
CCC	Comprehensive Care Centre.
DDAVP	Desmopressin (also known as DDAVP**,** which stands for 1-deamino-8-D-arginine vasopressin) is a synthetic medicine that boosts levels of factor VIII (FVIII) and von Willebrand factor (VWF) and can help prevent or control bleeding in patients with mild haemophilia A and von Willebrand's disease
ED	Emergency Department
Emicizumab	Emicizumab (trade name Hemlibra) is a humanized bispecific antibody for the treatment of haemophilia A. It functions by bringing together other blood clotting factors to promote clotting and reduce bleeding, in the absence of factor Vlll.
Factor	Factor concentrate is the usual treatment for people with bleeding disorders and replaces the factor protein that is missing
FEIBA	A 'by-passing agent', also known as activated prothrombin complex concentrate (aPCC) or Anti-Inhibitor Coagulant Complex. It is approved for use in haemophilia A and B patients with inhibitors for control and prevention of bleeding episodes.
Further Consideration	These are areas that may benefit from further attention by the service. They are not mandatory but based on the experience of the review team, it is felt who feel that the service could be enhanced through their implementation.
Good Practice	These are aspects of a service that are felt to represent an example of something that has been done particularly well compared to other Centres. It is recognised therefore as something worth sharing with other organisations.
HC	Haemophilia Centre
HCPA	Haemophilia Chartered Physiotherapists Association.
HNA	Haemophilia Nurses Association.
Haemnet	Haemnet is a community for allied care professionals who treat people with bleeding disorders. Haemnet supports health and social care professionals to ensure that excellent care becomes an everyday experience for people with bleeding disorders.
Haemtrack	Haemtrack is a secure recording system developed to connect patients and clinicians through the Haemtrack phone apps and website. Haemtrack enables patients to record all therapies as they occur, and allows clinicians to see up-to-date therapy information to help monitor, optimise and improve patient care
IABD	Inherited and acquired bleeding disorders
Immediate Risk	An immediate risk is a risk to clinical safety or outcomes, or to staff members**.** Immediate risks are defined as potential Serious Incidents, that is, situations in which a Serious Incident could occur in the circumstances found by the reviewers. Immediate Risks require urgent attention and a formal response by the Trust.
MDT	Multi-disciplinary Team

NEWS	The National Early Warning Score is a tool developed by the Royal College of Physicians which improve the detection and response to clinical deterioration in adult patients. It is a key element of patient safety and improving patient outcomes
NHD	The UK National Haemophilia Database (NHD) is a register of people in the UK with all types of bleeding disorders. It started in 1969. Its purpose is to improve the care of people with bleeding disorders. Data collected includes diagnosis, management and complications of bleeding disorders.
NovoSeven	Recombinant factor Vlla (rVlla). This is an agent used in patients with haemophilia and inhibitors, and sometimes also in acquired haemophilia.
Prophylaxis	Prophylaxis is the name given to regular treatment to prevent bleeds. It helps the blood to clot and minimises the likelihood of bleeds and long-term joint damage.
Radiation synovectomy	Radiation synovectomy is a very effective and gentle procedure, used for rapid and sustained pain relief in 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
Ready Steady Go	'Ready Steady Go' is a structured, but where necessary adaptable, transition programme. A key principle throughout Ready Steady Go is 'empowering' the young person to take control of their life and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both paediatric and adult services.
Recombinant	This describes a synthetically engineered factor product, rather than one derived from human or animal plasma, which therefore avoids the risk of a transfusion-transmitted virus or other infection.
UKAS	This is the UK's National Accreditation Body, responsible for determining, in the public interest, the technical competence and integrity of organisations such as those offering testing, calibration and certification services.
UKHCDO	UK Haemophilia Centre Doctors' Organisation

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APPENDIX 4 Summary of Compliance with Standards

Ref	Quality Standard (short Title)	Met	Not Met	N/A
HP-101	Service information	34	3	0
HP-102	Condition-specific information	31	6	0
HP-103	Plan of care	27	9	0
HP-104	Review of plan of care	29	7	0
HP-105	Contact for queries and advice	37	0	0
HP-106	Haemtrack (patients on home therapy)	35	2	0
HP-194	Environment	29	8	0
HP-195	Transition to adult service and preparation for adult life	30	7	0
HP-198	Carers' needs	21	16	0
HP-199	Involving patients and carers	28	9	0
HP-201	Lead consultant and lead nurse	34	3	0
HP-202	Staffing levels and skill mix	8	29	0
HP-203	Staffing competencies and training plan	12	25	0
HP-204	Competencies – all health and social care professionals	29	8	0
HP-299	Administrative, clerical and data collection support	28	9	0
HP-301	Support services	35	2	0
HP-302	Emergency Department – staff competences	28	6	3
HP-303	Laboratory service	36	1	0
HP-304	Specialist services	37	0	0
HP-402	Facilities and equipment	29	8	0
HP-499	IT system	28	8	0
HP-501	Diagnostic guidelines for patients with suspected inherited and acquires bleeding disorders	27	10	0
HP-502	Guidelines: Concentrate use and monitoring	32	5	0
HP-503	Clinical guidelines	25	12	0
HP-504	Emergency Department guidelines	29	7	1
HP-505	Guidelines on the care of patients requiring surgery	33	4	0
HP-595	Guidelines on transition and preparing for adult life	31	6	0
HP-599	Care of vulnerable people	37	0	0
HP-601	Service organisation	28	9	0
HP-602	Multi-disciplinary team meetings	32	5	0
HP-603	Multi-disciplinary clinics	24	13	0
HP-604	Liaison with other services	15	22	0
HP-701	Data collection	32	5	0
HP-702	Audit	11	26	0
HP-706	Research	31	6	0
HP-798	Multi-disciplinary review and learning	29	8	0
HP-799	Document control	13	24	0
Network				
HY-199	Involving patients and carers	15	22	0
HY-203	Inherited and acquired bleeding disorders network leads	8	29	0
HY-204	Education and raining	13	24	0
HY-503	Guidelines	9	28	0

Ref	Quality Standard (short Title)	Met	Not Met	N/A
HY-701	Ongoing monitoring	14	23	0
HY-702	Audit	2	35	0
HY-703	Research	9	28	0
HY-798	Network review and learning	11	26	0
Commissioning				
HZ-601	Commissioning of services	18	19	0
HZ-701	Clinical quality review meetings	9	28	0
HZ-798	Network review and learning	9	28	0

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APPENDIX 5 Immediate Risks

(Note: Seven immediate risks were identified at 6 Centres. The detail included in this Appendix has been taken directly from the Immediate Risk letter which was sent to the Trust as part of the immediate risk process).

Training

Children were treated by adult trained nurses who did not have any paediatric resuscitation or life support training and a paediatric doctor (who did have Advanced Paediatric Life Support training) was not always present at the time. In addition, although there was a paediatric team on site together with a paediatric cardiac arrest team who managed any emergencies at the neonatal unit, there was no agreed protocol in place for haemophilia centre staff to access the paediatric cardiac arrest team or for them to know who they should call in an emergency. Reviewers observed that a child could need resuscitation while in the Centre, and that a member of staff with appropriate competences to lead the resuscitation would not always be immediately available on the team. As there was no clear guidance in place as to how the paediatric resuscitation team should be called in such an emergency there was therefore a risk that starting appropriate resuscitation efforts could be delayed.

Emergency Department Guideline

In the 'short guide' for use in the ED and in the guidelines intended for managing patients at Emergency Departments in other hospitals, 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**.** If administered, this large dose would lead to serious clinical consequences**.**

Training

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 having blood transfusion, and factor administration which could give rise to anaphylaxis. It is essential that at all times, when patients are receiving treatment, sufficient staff working in the Centre have up to date training in at least Basic Life Support.

Clinical Guidelines

1. In the management of acute joint bleeds, it was not stated that for patients receiving Emicizumab, Feiba is contraindicated, as in combination these agents can lead to thrombotic microangiopathy and venous thrombosis. These patients should instead receive NovoSeven.
2. In a guideline on the treatment of von Willebrand Disease, the dosing instructions for Voncento™ were not clear. This contains both factor VIII and von Willebrand's factor [RiCof]. The guideline needs to be clear about which component is being used for the body weight-related dosage instruction. This is because there is a more than two-fold difference in the concentration of the two in the product.
3. The guideline on antenatal care, genetic testing and delivery did not include the need to undertake fetal gender testing at 9/40 (nine weeks' gestation). It also suggested undertaking chorionic villus biopsy [CVS] or cordocentesis at 20/40; CVS should be undertaken at approximately 11/40. Additionally, cordocentesis is seldom undertaken for pre-natal diagnosis of these disorders.
4. The same treatment guidance included the use of DDAVP but did not specify that this was only useful in some patients with haemophilia A, but not patients with haemophilia B or other conditions.

Clinical Guideline

In the clinical guideline for the treatment and management of acute joint bleeds, it was not stated that in patients receiving Emicizumab, Feiba was contraindicated, as in combination these agents can lead to thrombotic microangiopathy and venous thrombosis, and that instead they should receive NovoSeven.

Clinical Guideline

The guideline for the administration of factor IX did not include the risk of anaphylaxis due to inhibitor formation or the need for the first twenty doses to be administered in a suitable hospital setting and not at home.

Staffing

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

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Appendix 6 Summary of Evaluations

The figures and comments below summarise the evaluations undertaken during the course of the peer review programme including:

a. Reviewers' views – based on the evaluation forms completed by reviewers on the day of each review visit.

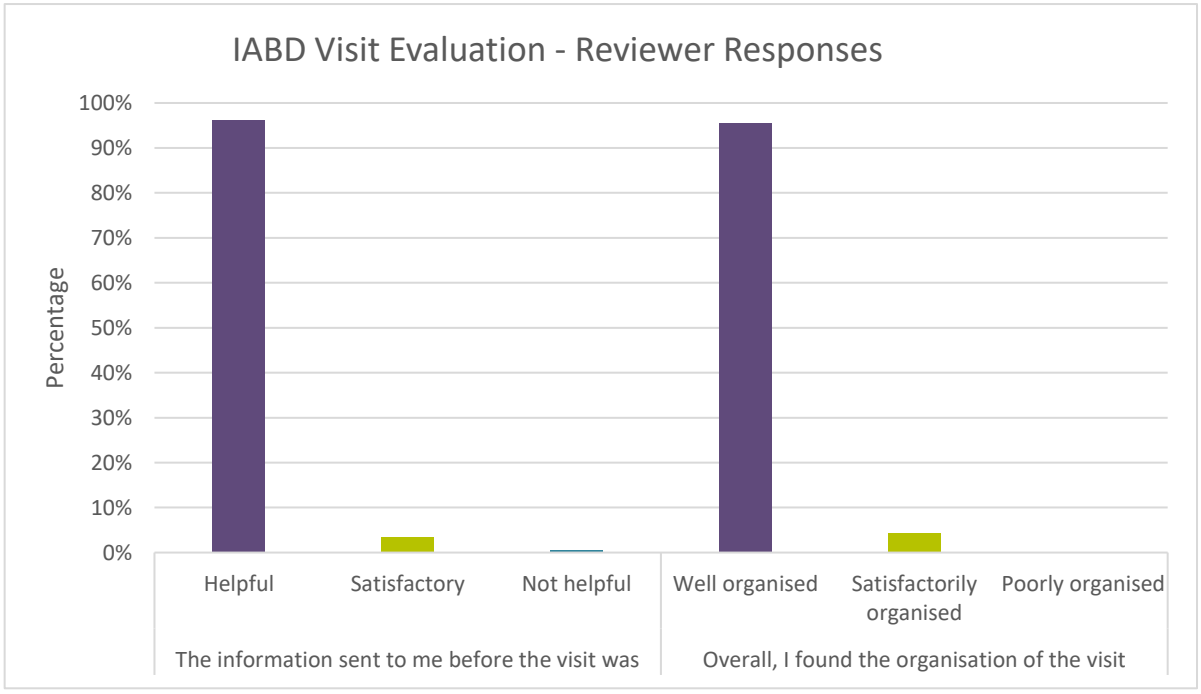
b. Evaluation from those being reviewed – based on an email evaluation from the Centre lead contact shortly after the review visit.

c. Product evaluation – based on online evaluation forms completed by the Centres in January/February 2020, following the end of the programme.

Note: *The number of comments on any issue is given in brackets alongside the comment made. The number of comments is=1 unless otherwise stated.*

Reviewers' Views

Evaluations issued to 219 reviewers. 207 responses. Response rate 95%



What went well
Good pre-visit information and travel/accommodation provided (27)
Good overall leadership and coordination of the reviewing team (53)
Timing - kept to programme (51)
Flow of the day (20)
Clear instructions and guidance (13)
Centre team very welcoming, informative (50)
Evidence - well organised (19)
Organised and professional (62)
Walkabout of facilities (10)
Teamwork of review team (42)
Networking opportunities (3)
Shared learning (12)
Meeting patients and carers (6)
Good, positive process (21)
Fantastic opportunity (6)
Online training (3)
Catering (1)

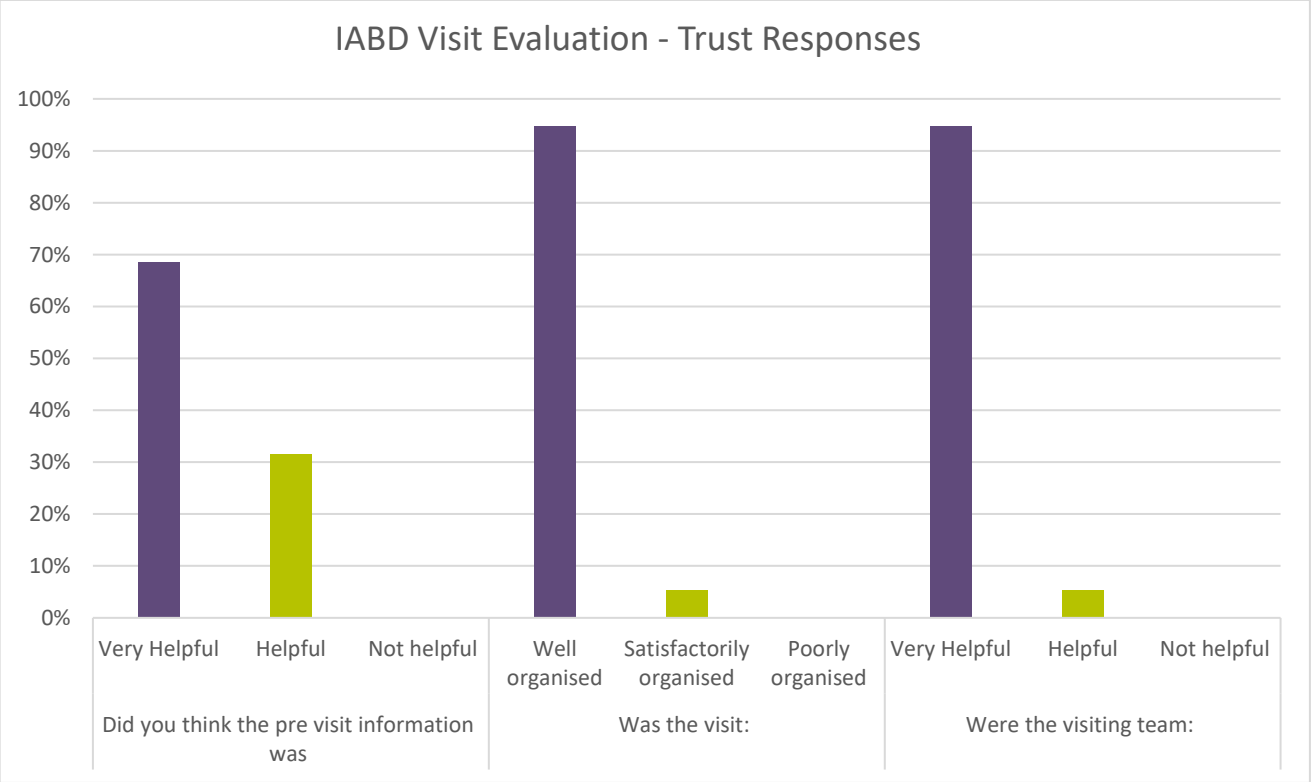
What didn't go so well
Arrival arrangements (7)
Time available (14)
Time management (Trust not following timetable) (6)
Information/evidence provided by site (19)
Site including signage, traffic and parking (12)
Base room (9)
Tour of the facilities (7)
Visiting review team (2)
Availability of host staff (11)
Meeting more patients (1)
Organisation of service (2)
Catering (5)

Any suggestions/comments you feel would help improve the process
Suggestions:
Host staff being more informed so that they are available and know what is expected (5)
Time to speak to peer on 1-1 basis would have been good (2)
Guidelines / recommendations provided for review Centres on how to provide evidence (3)
More access to patient notes on site / documents / guidelines beforehand (7)
Walk around service should have come before evidence review (1)

Any suggestions/comments you feel would help improve the process
Examples of patient flow (2)
Interpretation, understanding and repetitiveness of some Standards (7)
More support for patient reps (2)
Complete training closer to review (1)
Make it mandatory that a member of the management team is interviewed (2)
Provide car park advice (1)
Provide copies of previous reports (1)
Suggest reviewers go on more than one visit (1)
Improve visit timings (3)
Improve venue / catering arrangements (3)
Comments:
Good visit / Enjoyable / rewarding process (18)
Having done it once has prepared me how to do it better next time (2)
Interesting / helpful lessons learnt (1)
Well organised/ planned (7)

Trust Views

Trust evaluations issued for 37 visits. 19 responses received. Response rate 51%



What went well
Timetabling (3)
Keeping to time (4)
Leadership of review (3)
Feedback (5)
Enjoyable
Review team (9)
Organisation (6)
Useful process (3)
Meetings

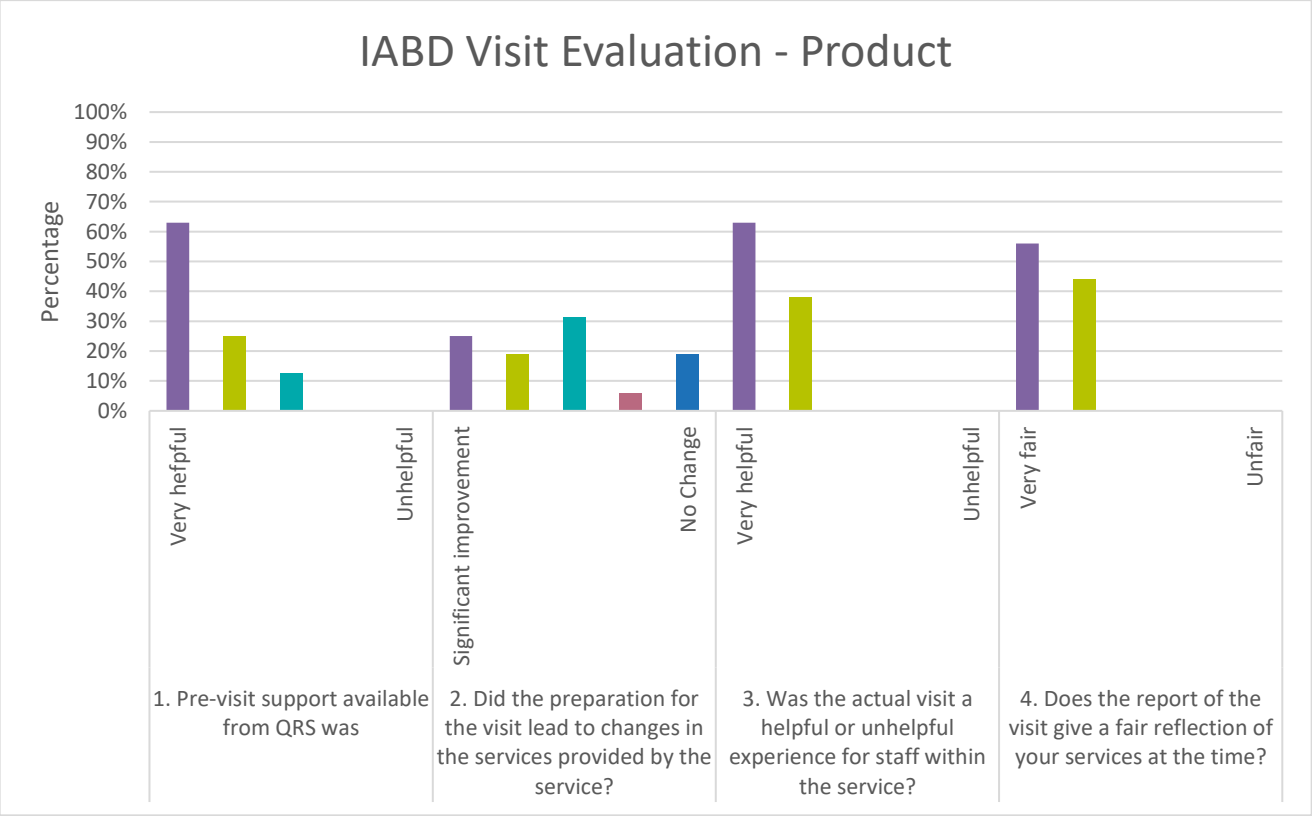
What didn't go so well
Late arrivals (reviewers)
Evidence not available (3)
Changes to timetable (3)
Timing (3)

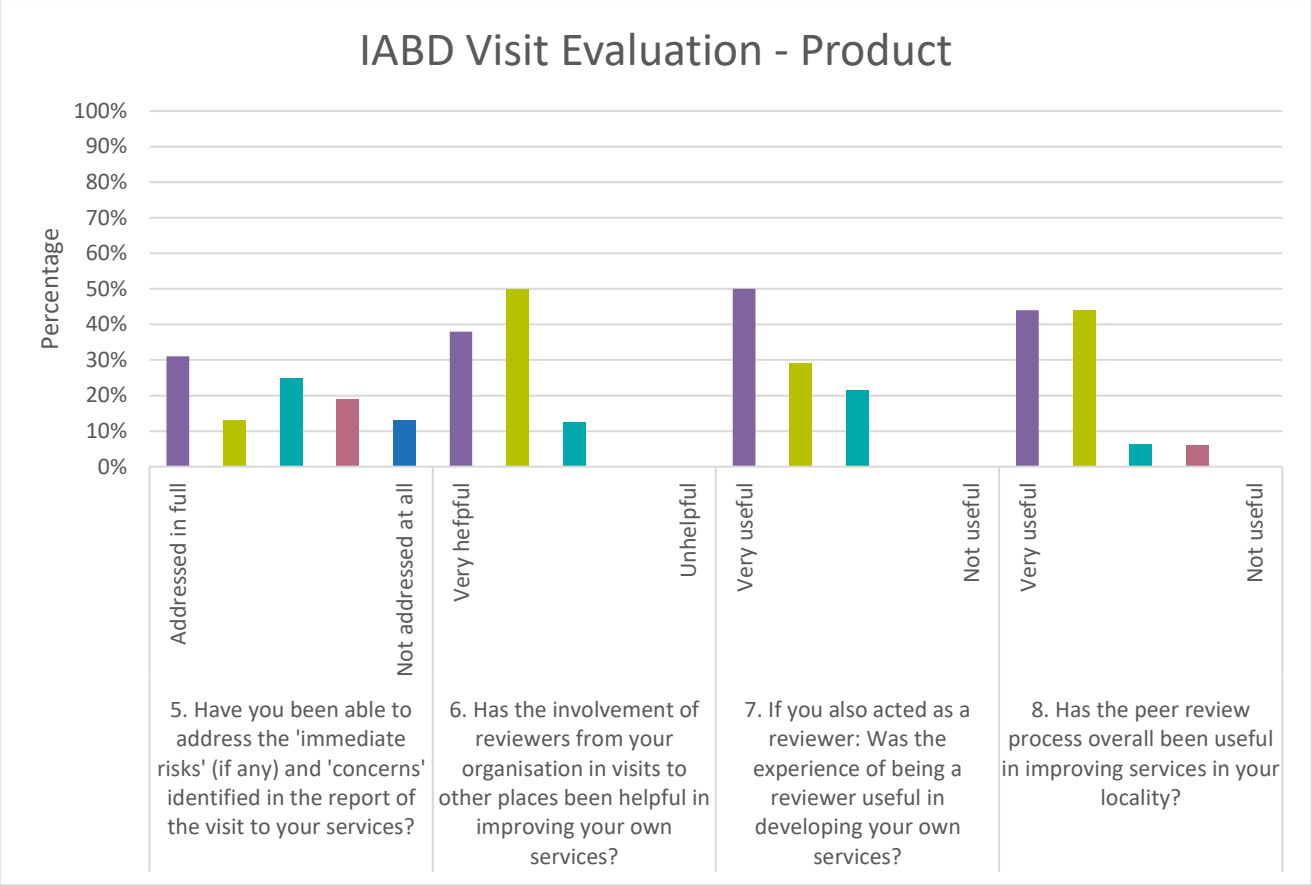
Any suggestions/comments you feel would help improve the process
Suggestions:
Review of Quality Standards Highlight applicable standards
Suggest Centres cancel clinics on day of review
Separate meeting for nurses, physios and social workers
Engage management – timetable a meeting
Training e.g. mock review folders

Any suggestions/comments you feel would help improve the process
Nominate a lead for planning
Comments:
Excel self-assessment sheet hard to work with
A lot to cover in one day
The Standards were viewed objectively
Thorough review of all aspects of service
Helped being a reviewer

Overall Evaluation

Overall evaluations issued for 29 visits (eight not yet due for issue). Fourteen responses. Response rate 55%.





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APPENDIX 7 Summary of recommendations

Recommendations

1a. Teams need to ensure that service and condition–specific information is available in different formats and that it is routinely given to patients, particularly those who have attended the Centre for some time, as information and contact points may have changed since the patients received information when they were first diagnosed.

1b. Care plans and clinical letter proformas should cover all the main elements of Quality Standard HP-103, and should routinely be copied to patients, and parents or carers of children.

1c. Efforts are needed to ensure that appropriate office space for staff to work from, and clinical treatment space is available.

1d. Further work is needed on providing clear signage to Centres. Although most patients have been attending their Centre for many years and knew where to go, this would not always be the case for new patients.

1e. Consideration should be given to providing designated parking spaces close to the Centre. Some patients may be attending with an acute joint bleed which would make walking any distance difficult, and other patients may have mobility issues.

1f. All Centres should ensure that the transition process is carefully managed, and that young people and their families are fully informed and supported at every stage of the process. This will help to improve patient experience and continued adherence to treatment during this vulnerable stage.

1g. Centres are encouraged to ensure that there is a greater focus on carers needs and improved access and signposting to services that are widely available through the Trusts or via other third party and charity sectors.

1h. A more formal mechanism for inviting feedback from all users, who may not volunteer their views, is recommended to inform service improvement. When issues are raised, efforts should be made to address them, to implement appropriate change where possible, and to communicate any changes back to service users: 'You said, we did'.

1i. The Specialised Blood Disorders Clinical Reference Group should lead a review of the homecare delivery service in order to ensure that patient experience is improved, and the service is more responsive to patient needs.

2a. Meeting staffing and skill mix requirements in teams managing IABD services is a national challenge that needs to be urgently addressed. Stronger networking arrangements, and improved commissioner engagement, will be required if progress is to be made.

2b. A review of job descriptions and plans for staff currently in post is required to ensure that they have the appropriate time to undertake their leadership roles, as well as the necessary training and professional development.

2c. A guide to the minimum ratios of the number of staff to the number of patients treated, outlining the time required for key tasks for each role, should be developed by UKHCDO / the Specialised Blood Disorders Clinical Reference Group as a key resource to support Centres in responding to these challenges, and progress should be made towards a commissioned workforce plan. This must include all key MDT roles and not just focus on medical and nursing time.

2d. A basic competency framework that services can adapt to their unique requirements should be available to define skills and training requirements.

2e. All Centres must ensure that clinical staff are up to date with key statutory and mandatory training including Basic Life Support for adults and / or children, according to the age ranges of the patients they manage.

3a. Continued efforts are required in all Centres in order to ensure that ED staff have an understanding of the immediate management of patients presenting with bleeding disorders know who to refer to in a timely manner and respect the fact that patients with long-term conditions have considerable knowledge and expertise.

4a. Consideration should be given to rolling out the ambulance systems that were seen in two Centres enabling ambulance crews to easily identify that a patient had a bleeding disorder.

4b. There should be an alert on the Trust electronic patient record system indicating that the patient has a bleeding disorder.

4c. There should be an automated alert from the ED confirming that a patient with bleeding disorder has attended the ED. Centres where there is no alert from the ED system should be encouraged to work with their Trust IT teams to ensure that this relatively basic functionality can be implemented.

4d. Centres should ensure that fridges, in which factor concentrates are stored are secure, with access only for appropriate staff, and that temperature monitoring is in place with an alert system that is triggered if there is a variation in the temperature outside the required range.

5a. Centres should ensure that current guidelines and other documentation are complete, up to date, explicit about local implementation, and readily accessible to staff to ensure that staff are aware of what they should do and so that safe practice can be maintained.

5b. Many of the guidelines are fairly generic, so there is opportunity for Centres to share guidelines that were identified as good practice.

5c. The UKHCDO should consider establishing a portal on its website, giving access to commended guidelines submitted by Centres willing to share them, for adoption and approval at other Centres.

5d. Guidance to avoid the use of activated prothrombin complex concentrates (aPCC, 'Feiba') in patients with inhibitors who are receiving Emicizumab (as in combination these agents can lead to thrombotic microangiopathy and venous thrombosis), should be circulated by the UKHCDO to all treating centres, with the request that they include this caution in their clinical guidelines, and recommending instead, the use of recombinant factor VIIa (rVIIa, 'NovoSeven') for treating a bleeding episode.

6a. Each Centre should review the adequacy of their operational policy, ensuring it covers the elements of HP-601.

6b. At all Centres, MDT meetings should be minuted and include action logs with the names of individuals who will be responsible for ensuring that the actions are completed. Any decisions reached after discussion should be included in the applicable patient's records.

6c. Clearly documented communication is needed between clinical teams when co-managing patients, and patients should receive copies of this to reassure them that their speciality team is appropriately involved in care planning.

7a. Centres need to prioritise service quality reviews and audits to help them understand and evidence the quality of the service that is being delivered and identify areas for improvement.

7b. Any planned changes to patient care arising from MDT discussions should be documented in the patients' medical records.

7c. In those Centres in which review and learning meetings are taking place, the Centres should ensure that these meetings are documented and that action plans include details of those responsible for taking actions forward.

7d. In Centres where review and learning is not embedded, action is needed to ensure that this important activity is implemented and embedded in the routine activity of the team.

7e. Work is required in the majority of Centres to ensure that Trust policy on document control is implemented for all guideline and policy documents supporting the service. If documents include authorship and review details, it is clear to all staff what the latest version of the document is and who they should refer to if they are unclear, reducing the risk of errors.

7f. Patients in all Centres should be made aware of the research studies for which they would be eligible and offered entry to them.

7g. Document control was either missing or not robust in about two-thirds of Centres. Poor document control can lead to the wrong version of a procedure being used or changed. Robust document control procedures underpin high quality policies and procedures.

8a. Commissioners should be explicit about the network arrangements they expect to be in place, and to give adequate resources to the CCC teams to lead and develop their networks.

8b. Each network needs to have nominated leads for each professional group – consultant, nurse specialist, physiotherapist, psychologist and manager.

8c. Networks should meet at least once a year to discuss service developments, to study data from each Centre, to review audits and action plans, and to have review and learning discussions arising from any complaints or incidents.

8d. Network-wide educational sessions should be offered.

8e. Feedback from patients treated at all Centres should be collated and discussed.

8f. Specialist teams should review job plans in order to offer some outreach clinics wherever possible as part of the network arrangements, to reduce inconvenience and travelling time for patients and families, and to offer educational opportunities for staff at smaller Centres.

8g. Teams should also focus on strengthening informal links with colleagues at the DGHs that their patients might attend in an emergency.

9a. Urgent discussions are required at the Specialised Blood Disorders Clinical Reference Group meeting, and between other key stakeholders, regarding the substantial variation in commissioner engagement, the extent and type of network functioning and inequalities in service quality across the UK for children and adults with IABD.

9b. Commissioners need to be explicit about the network arrangements they expect to be in place, and to give adequate resources to the CCC teams to lead and develop their networks.

9c. Commissioners should regularly review the quality of the service provided at each Centre, as evidenced by data submitted regarding factor use and bleed frequency, and clinical audit findings.

9d. Commissioners should attend network meetings at least annually and take part in review and learning discussions.

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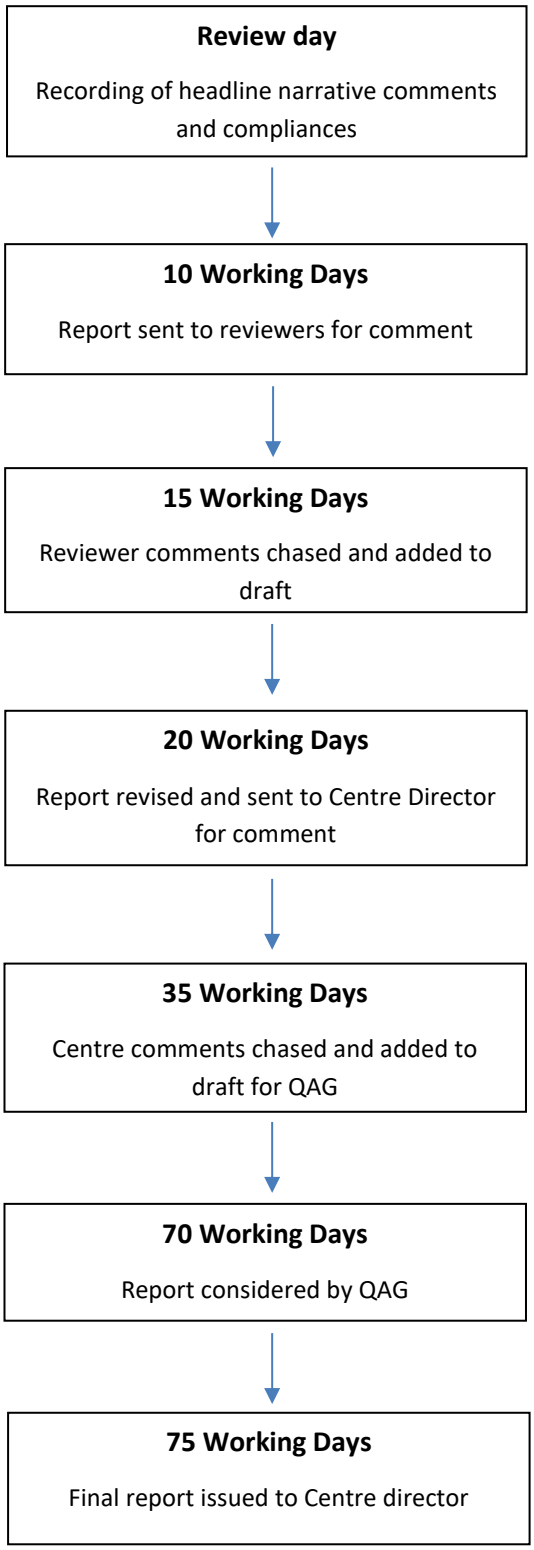
APPENDIX 8 Report Writing and Quality Assurance Timeframe

[Note: these are based on QRS target deadlines. In practice, all of the reports for this programme were issued well within these timeframes]



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