*Draft Report for Quality Assurance Group **

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

Hull and East Yorkshire NHS Trust

Visit Date: 20th November 2018

*Quality Assurance process TBA with UKHCDO

Max WD		Date	WMQRS standard met? Y/N	Actual WD	Initials	Comments
0	On day recording of issues and compliance. Backed up.	20.11.18	Y	0	RB	
5	Compliance written and checked (N/A if lead also writing issues)	26.11.18	Y	4	RB	
10	Issues written	21.11.18	Y	1	AY	
10	Report sent to reviewers for comment	28.11.18	Y	6	RB	
20	Report revised and sent to HE for comment	06.12.18	Y	12	RB	
35	Comments received from HE	21.12.18	Y	23	DA	
40	HE comments incorporated into draft report	04.01.12	Y	30	RB	

INDEX

INTRODUCTION

This report presents the findings of the peer review of services for people with Inherited and Acquired Haemophilia and other Bleeding Disorders at Hull and East Yorkshire NHS Trust on the 20th November 2018.

The purpose of the visit was to review compliance with the Quality Standards for Inherited and Acquired Haemophilia and other Bleeding Disorders (V1 July 2018) which were developed by the UKHCDO Peer Review Working Group working with the West Midland Quality Review Service (WMQRS).

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

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

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

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

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

- Hull and East Yorkshire NHS Trust
- NHS England: Specialised Commissioning (Yorkshire and Humber)

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners.

Acknowledgements

We would like to thank the team at the Hull Haemophilia Centre for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team.

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

About West Midlands Quality Review Service

WMQRS is a collaborative venture by NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved.

More detail about the work of WMQRS is available at www.wmqrs.nhs.uk

Return to *Index*

Hull and East Yorkshire NHS Trust

The Hull Haemophilia Centre serves a population of approximately 927,000 derived from the East Riding of Yorkshire, Hull, North Lincolnshire and North East Lincolnshire Clinical Commissioning Groups. They treat patients with Inherited and Acquired Haemophilia and other disorders of haemostasis and provide a service to adult and paediatric patients which includes dedicated multidisciplinary severe haemophilia clinics for adults and children and obstetric clinics. There were nurse-led clinics in which patients with mild bleeding disorders are supported and reviewed. The core membership of the MDT included two consultant haematologists and one paediatric trained haematologist, four haemostasis nurses (3WTE), two administrators, one coagulation biomedical scientist, one data manager, one haemophilia physiotherapist and one pharmacy technician. The team interacted closely with the regional Comprehensive Care Centre at Sheffield Teaching Hospitals Trust.

The Centre is responsible for patients with a range of conditions, as follows:

Condition		**No. patients (show breakdown Severe, Moderate and Mild)**			**No. patients who had an annual review in last year**	**No. in-patient admissions in last year**
		Severe	**Moderate**	**Mild**		
Haemophilia A	Adults	20	2	52	74	14
	Children	5	1	9	15	1
Haemophilia B	Adults	7	2	1	10	3
	Children	3	1	1	5	0
Von Willebrand	Adults	92			92	12
	Children	37			37	1
Other	Adults	117			101	38
	Children	48			48	1

Ward Care:

This facility was not specific to patients with bleeding disorders. Adult patients were managed at Queen's Centre for Oncology and Haematology, Castle Hill Hospital. Nurses with Acute oncology training managing acute haematology and oncology patients including administration of intensive chemotherapy and autologous stem cell transplant. Medical cover was provided by a Consultant Haematologist, Haematology specialist registrars and Foundation 2/Core Trainee 1 doctors. Paediatric patients were managed on the paediatric wards based at Hull Royal Infirmary.

Day Unit Care:

This facility was not specific to patients with bleeding disorders. Nurse-led facility for adults was functioning to administer chemotherapy and supportive treatments for haematology and oncology patients. Medical cover was provided by Haematology Specialist Registrars with Consultant Haematologist cover as required. Any day care for paediatric patients is administered either at the paediatric out-patient clinic, Women and Children's hospital, or the Paediatric Assessment Unit, Hull Royal Infirmary.

OUTPATIENTS:

This facility was not specific to patients with bleeding disorders. Adult out-patient care was based at the Queen's Centre for Oncology and Haematology, Castle Hill Hospital whilst the paediatric out-patient care is based at the Women and Children's hospital, Hull Royal Infirmary.

COMMUNITY BASED CARE:

Haemostasis specialist nurses reviewed patients in their own home for administration of prophylaxis and treatment including education and training. They also attended schools and nurseries for appropriate staff training.

Return to *Index*

REVIEW VISIT FINDINGS

General Comments and Achievements

Sited across two separate facilities, this large Haemophilia Centre had no specific or dedicated physical space, but it worked well as a coherent and functional Centre, largely due to the focus of its team members, and excellent communication between them. Efforts had been made within the Queen's Centre for this function to be visible, and the space was welcoming for its users. The physical environment at the Queen's Centre was excellent; that on the Hull Royal Infirmary site was pleasant and spacious.

Reviewers felt that this was a very strong service, although not well resourced especially in medical staffing (see concerns section below). This was reflected in the extremely warm and appreciative patient feedback. There was an excellent, flexible and responsive specialist nursing team. The efforts taken by the part time physiotherapist, the data manager's input to the work of the centre, and the involvement of the bio-medical scientist were noteworthy.

Patients with bleeding disorders could nearly always be managed at the dedicated Haematology Ward 33 (Castle Hill hospital). Children were seen in the Paediatric Assessment Unit (PAU) at Hull Royal Infirmary for treatment before being discharged home. Children who were admitted went to Acorn Ward at the Hull Royal Infirmary. Those of the relevant age group could be accommodated, and were welcomed, in the Teenage and Young Adult facility where they received excellent support from nursing staff working in inventive ways with all the patients in this age group.

Good Practice

1. Patients' feedback comments, and actions taken in response to them, were displayed and updated every month.
2. Families were invited to make direct contact, out of hours, with the Haematology medical team, via switchboard, if they had any concerns relating to their bleeding disorder or considered that they may require admission. Daytime contact with the specialist nurses, via a bleep and or mobile phone, similarly ensured quick access to appropriately knowledgeable staff
3. Transition practice, for teenagers moving from the paediatric to the adult service, was excellent. The change was made easier by the nursing team and physiotherapist working across the two services but it was nonetheless clear that effort and focus had been put into managing this potentially difficult time for young people.
4. 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.
5. The Haemophilia Centre had a sophisticated and comprehensive website which ensured that information was easily accessible by patients and carers and this was reflected in the feedback from the patient forum which was held as part of the review.
6. The initial clinic consultation letter for each child was copied to the Comprehensive Care Centre in Sheffield, so that the team there were aware of them and had records on file in case of future contact being necessary.
7. The reviewers were impressed by the enormous efforts made by the team, involving other relevant teams within the Trust, to provide special care facilities for one patient with severe haemophilia and learning difficulties. This was provided in a carefully designed clinical room dedicated for his use.

Immediate Risks

There were no immediate risks.

Concerns

1. **Staffing**
    a. Paediatric support for the adult Haematologist leading the paediatric service was inadequate, and while the service functioned well, reviewers felt that this left her potentially vulnerable when managing specific paediatric issues. Senior managers were aware of this concern, but it had not yet proved possible to resource the service appropriately.
    b. The adult service lead had insufficient PA's identified in his job plan to manage a service of this size, and both he and the paediatric lead were also working across a range of other haematology sub-specialties. Consultant PA allocation across both sides of the service were not adequate for the demands of the leadership positions. The fact the service functions well is a credit to both of these individuals, but reviewers felt that this was not sustainable.
    c. There is no cover for the physiotherapist, who is in a part time post (0.6 WTE). Reviewers felt that this needed to be reviewed in order to ensure that this service was appropriately resourced both for patients and staff.

2. **Network Arrangements**

    This service was commissioned as part of a managed network, with Sheffield Comprehensive Care Centre being its linked specialist site. While clinical support from the Sheffield team was readily available, other expected network functions did not appear to be in place, including shared education and training, agreed guidelines, governance arrangements and review and learning. Meetings for teams across the network had not taken place for a long time. Communication with commissioners, which should have been through network meetings, was therefore also lacking. Reviewers noted that responsibility for improving this situation does not rest solely with the Hull team.

3. **Children being treated in adult sessions**

    Reviewers heard that on some occasions, children were being seen in therapy sessions alongside adults. It was noted that this was due to the capacity of the physiotherapist however it remained inappropriate and ways to separate out appointment times should be sought so that this does not occur.

4. **Pathology services**

    Reviewers heard that it was not possible to perform simple coagulation screen tests, or factor assays, on the Castle Hill site despite analysers capable of running these tests being available and National External Quality Assessment Service (NEQAS) quality assurance checks were being submitted for them. There was concern about how patients could be optimally managed getting results back for these tests from the Hull Royal Infirmary laboratory, could often take two hours or more.

Further Consideration

1 There was some duplication of documents, with older and newer version both being in use. For example, the user's guide to the Queen's Centre was available as an older more generic guide with a section about the Haemophilia Centre and there was also a newer version with some different information but which did not seem to contain all of the relevant information in the previous version, and it was not clear if users were being given both versions. Also, a good guideline for the management of bleeding disorders in the Emergency Department had been updated, with clearer advice about numbers to call to access the specialist team, but both versions appeared in evidence in different sections.

2 Comprehensive care plan proformas were seen in evidence, and in some of the patients medical records presented, but this was inconsistent: not in all sets of notes and not for all annual reviews. It was not therefore clear these were being consistently completed. If they were, and copies were sent systematically to patients, these would be a helpful and sufficient record of the regular reviews.

3 Reviewers saw a wide range of condition specific information leaflets for patients. However, feedback suggested that these were not always being shared proactively with patients. The team should ensure that all team members are reminded to proactively share information with patients not just at diagnosis but on an ongoing basis, as new guidance material is developed.

4 Reviewers heard that funding for some laboratory work was reported to be limited, and staff felt they had to justify ordering even day to day reagents and other requirements, and ideas for development were difficult to progress. This needs to be investigated to ensure that staff have access to appropriate resources in order to provide appropriate diagnostics for care and treatment.

5 Consideration should be given to updating two of the routine laboratory tests: Von Willebrand Factor activity was being measured, rather than the now more frequently run RiCoF, and a urea solubility test for Factor Xlll activity has also now generally been superseded by a new methodology.

6 Reviewers heard from patients that they would always prefer to access care in the specialty areas, rather than the Emergency Department at Hull Royal Infirmary, where they reported that care can be inconsistent. They felt they needed to be assertive to get appropriate care there, and sometimes to guide clinicians as to what was required.

7 Reviewers felt that as all of the specialty nursing team were based at the Queen’s Centre, this could lead to delays in them reaching acutely unwell patients at Hull Royal Infirmary; delays included not just distance but also difficulty finding parking at the hospital sites on arrival.

8 The self-assessment indicated that a recommended rolling programme of audit was not in place; it was noted however that several audits were in place, including: entry of compliances onto the Haemophilia Database; regular auditing of patient feedback; compliance and adherence to the national contract ensuring that patient treatment was in line with national guidelines. The MDT agenda also showed regular review / audit of patient management. However, consideration should be given to producing a programme of systematic audits including care elements against the Centre’s clinical guidelines, initiation of prophylaxis and emergency and out of hours care.

NETWORK

There was non -compliance with all of the Network standards.

At the time of the visit, although there were identified working relationships with the Comprehensive Care Centre at Sheffield Teaching Hospitals NHS Trust, this was not a formal network arrangement in place (see Concerns section above).

COMMISSIONING

There was non-compliance with all the commissioning standards. See reference to Network arrangements above.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team		
Cathy Benfield	Paediatric Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Caroline Clegg	Acting Clinical Lead Rheumatology/Haematology Therapy Team	Manchester University NHS Foundation Trust
Claire Forrester	Haemophilia Nurse Practitioner	University Hospitals of North Midlands NHS Trust
Dr John Hanley	Consultant Haematologist	Newcastle Upon Tyne Hospitals NHS Foundation Trust
Dr Jayashree Motwani	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust
Paul Murphy	Healthcare Scientist	Newcastle Upon Tyne Hospitals NHS Foundation Trust

WMQRS Team		
Dr Anne Yardumian	Consultant Haematologist	Programme Clinical Lead
Rachael Blackburn	Assistant Director	West Midlands Quality Review Service

Return to *Index*

APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
TBC once compliance has been agreed with the host Centre			
Total			

Return to *Index*