UKHCDO HC AUDIT 2009

NAME AND ADDRESS OF AUDITED CENTRE
Northern Ireland Haemophilia and Thrombosis Centre
Bridgewater Suite
City Hospital Belfast
Belfast, NI

DIRECTOR **Dr Gary Benson**

STAFF GRADE **Dr Orla McNulty**

NURSING STAFF (Grades and WTEs)
CNS Colette McAfee (1.0) Band 6
SN Margaret O'Donnell (1.0) Band 6

AUDIT TEAM

MEDICAL AUDITOR **Dr Jonathan Wilde**

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PATIENT AUDITORS **Mrs R Cooper, Mr M Gregory**

DATE OF AUDIT VISIT **19th January 2010**

DATE OF SUBMISSION OF DRAFT AUDIT REPORT TO CENTRE
8th February 2010

DATE OF SUBMISSION OF FINALISED REPORT TO AUDIT CO-ORDINATOR **26th February 2010**

1. THE HAEMOPHILIA CENTRE

The audit team should note the location, layout, adjacencies etc. of the haemophilia centre and a full description of the centre should be included in the audit report.

See below

1.1 PATIENT SERVICES AT CENTRE

Standard – Patients, family members and carers attending the CCC should have easy access to the centre, adequate facilities whilst waiting, a private counselling area and availability of written information about all aspects of haemophilia and related disorders.

	ADEQUATE	INADEQUATE
Access by car	**Tick**	
Designated Centre Car Parking		**Tick**
Access by public transport	**Tick**	
Disabled access	**Tick**	
Direct Emergency Ambulance Access	**Via A and E**	
Signposting	**Tick**	
Direct telephone line	**Tick**	
Answerphone	**Tick**	
e-mail access	**Tick**	
Waiting area	**Tick**	
Toilets	**Tick**	
Disabled toilets	**Tick**	

	ADEQUATE	INADEQUATE
Play Area (in centre where children are treated)	**NA**	
List of up to date educational material	**Tick**	

COMMENTS

The Northern Ireland Haemophilia and Thrombosis Centre is an integral part of the Haematology / Oncology out-patient suite, the Bridgewater Unit, which is situated on the first level of the Belfast City Hospital tower block. The centre straddles the unit's main corridor and comprises a reception / administration office, a rest room and Dr Benson's office on one side of the corridor and a treatment room, the offices of Dr McNulty and the Specialist registrar, preparation room, toilet and nursing staff office on the other. The centre area is spacious, well lit, clean and in an excellent state of repair. There are examination couches in both Dr McNulty's and the registrar's rooms. The nursing office is somewhat cramped. It was noted that none of the rest rooms contained sanitary disposal facilities.

The regional haemostasis laboratory is situated within the hospital haematology laboratory which is just down the corridor from the centre.

UKHCDO database record at the time of the audit :
292 registered patients

41 with severe haemophilia A and B
2 patients with inhibitors
1 with Type 3 von Willebrands
2 with Bernard Soulier

90 patients treated during 2008

There is no dedicated car parking for bleeding disorder patients.

2. COAGULATION FACTOR STOCK CONTROL, STORAGE AND ISSUE

Standard – CCCs should have in place adequate procedures for factor concentrate ordering, storage, stock control, recording of issue to patients and use by patients.

2.1 Procedures for factor ordering

Satisfactory

2.2 Procedures for storage of concentrate

Satisfactory

2.3 Procedures for stock control

Satisfactory

2.4 Procedures for recording of concentrate issues to patients

Satisfactory

2.5 If home delivery service in place, adequate recording of concentrate issuing by company

Not applicable

2.6 Procedures for recording concentrate usage by patients on home treatment (e.g. home treatment recording system and return of this record to the centre)

Satisfactory

COMMENTS (To include a description of home delivery arrangements if in place)

A home delivery service has not been offered to patients as VAT is not applied to recombinant concentrates in NI so there would be no VAT savings to off set the delivery charge.
Patients place an order for factor by ringing or emailing the haemophilia centre and the order is prepared from the small supply of factor held in the hospital laboratory cold room. It is held in the cold room until the patient attends the centre for collection. The cold room is continually restocked from the Royal Victoria Hospital blood bank where

the main stock of concentrate is held. Patients are able to order and collect treatment on the same day if required. All factor orders, factor issue and factor receipt when delivered from the Royal Victoria are recorded on the laboratory computer system. An issue record report is printed off in the laboratory for filing in the patient's medical record.
For patients who live long distances from the centre factor orders are delivered to their local hospitals for collection.
Completed patient treatment records are returned to the hospital for filing in the patient's medical record. Those receiving treatment delivered to their local hospital have the option to record the treatment used on the delivery sheet itself and post it back to the hospital.

A small supply of factor is held in the centre refrigerator for emergency use but a further emergency supply is readily available from the laboratory cold room.

The audit team visited the blood bank at the Royal Victoria Hospital to check the arrangements for stock control and issue and these were entirely satisfactory. Stock reconciliation against issue takes place monthly and top up orders are then placed with companies. About two months supply of factor concentrate is held in the blood bank cold room.

3. TREATMENT

Standard – Patients who are actively bleeding receive prompt and effective treatment according to established protocols throughout the 24 hour period. Appropriate arrangements are in place for routine patient review and liaison with affiliated haemophilia centres for shared care patients. Adequate mechanisms and protocols are in place for home treatment, prophylactic administration of concentrate and management of inhibitor patients where appropriate. General and genetic counselling is readily available for patients and their families.

3.1. There is an appropriate treatment area that provides privacy and comfort

Satisfactory

3.2. Universal cross-infection precautions are in place

Satisfactory

3.3. There is effective recording of patients' vCJD at risk status and appropriate health care measures are in place for at risk patients.

Satisfactory
Medical records have status on front sheet. There is a section on vCJD risk in surgical protocols.

3.4. There is evidence of appropriate routine review of patients

Satisfactory
A multidisciplinary review clinic is held once a month with Consultant, registrar, Haemophilia Nurse and Social Worker in attendance.

3.5. There is in place a formalised pathway protocol for out of hours patient review and care

Satisfactory

3.6. Consultant haemophilia medical staff are available 24 hours a day for treatment advice.

Satisfactory

3.7. There is evidence of effective community liaison between the unit and the patient in their home and with primary care providers

Satisfactory

3.8. Written protocols / guidelines / procedures are available for the following:

	Satisfactory	Unsatisfactory	N/A
1. Management of bleeding episodes	Tick		
2. Commencement of home treatment / Venous access training	Tick		
3. Commencement of prophylaxis in children			Tick
4. Management of inhibitor patients (including immune tolerance)	UKHCDO Guidelines		
5. Treatment in Accident and Emergency	Tick		
6. Management of pregnancy and childbirth	Tick		
7. Genetic counselling	Tick		

3.9. List mechanisms in place for orientation of medical and nursing staff and for procedural training.

Junior doctors on rotation to the unit and newly appointed haematology nurses undergo formal orientation.

COMMENTS

A haemophilia follow up clinic is held on the unit once a month on a Friday morning. Patients with other bleeding disorders are seen on the other Friday mornings. On the first Tuesday of each month Dr Benson holds a haemophilia clinic in Londonderry reviewing

up to ten patients whilst Dr McNulty holds a carrier screening clinic on the unit. New referrals are seen in a clinic on Wednesday mornings. Other clinics include a general haemostasis / thrombosis clinic on a Monday afternoon and a DVT assessment clinic on a Thursday morning. On the fourth Tuesday of each month Drs Benson and McNulty hold a joint obstetric haemostasis / thrombosis clinic with Mrs Hunter at the Maternity Hospital. The team meets on a Monday morning to discuss patient issues and plan the week ahead.

Out of hours patients are requested to ring the nursing staff on the haematology ward. The on call resident doctor or SpR is contacted and if the patient needs to be reviewed they are directed to the Accident and Emergency department where they are seen by the SpR. If factor treatment is required this is readily available from the laboratory cold room. All bleeding disorder medical records are kept separately from the general medical notes files and are stored in the haemophilia unit office. Although the Bridgewater unit is locked out of hours the unit notes are accessed by contacting hospital security.

In-patient beds are on the haematology ward on floor 7 of the hospital but occasionally bleeding disorder patients have to be admitted to a general medical ward.

Junior medical cover out of hours is adequate. Dr Benson participates in a 1 in 3 on call rota covering all specialty areas with his fellow consultants Professor Francis McMullen and Dr Robert Cuthbert. Dr Benson is usually available for haemostasis problems when not on call but there is no haemostasis cover when he is away.

In-house protocols need to have review dates.

3.10 Relationship between Comprehensive Care Centre and neighbouring Haemophilia Centres

3.10.1. List of Haemophilia Centres in locality of CCC

Not applicable as no HCs in Northern Ireland

3.10.2. There is a formal network arrangement between the CCC and the neighbouring Haemophilia Centres

NA

3.10.3. If yes, assess the arrangement with regard to the following:

There is shared patient care	Yes	No
If so, shared care arrangements are satisfactory	Yes	No
There is effective liaison between the CCC and the HC for advice/ patient referral over the 24 hour period	Yes	No
There are shared treatment protocols/ guidelines	Yes	No
There are adequate arrangements for the supply of factor concentrate to the HC	Yes	No

COMMENTS

4. AVAILABILITY OF COMPREHENSIVE CARE SERVICES

Standard – Services required to provide a comprehensive care service are available as detailed in the Haemophilia Alliance National Service Specification.

A full description of these should be included in the free text audit report.

4.1. The following services / personnel are available;

	NAME	NOT AVAILABLE	N/A
Centre receptionist Centre secretary	Mrs Laura Ferris Mrs Donna McDoowell		
Centre data / business manager		Tick	
Dedicated Social worker	Ms Una McGiven Ms Ann McClosky		
Dedicated Physiotherapist		Tick	
Psychologist / Counsellor	Mr Roger McClements		
Dental service / Dentist (a full description of the service offered should be included)	Mr Brian Mulally		
Orthopaedic service / Orthopaedic surgeon	As appropriate		
General/Specialist surgical services	Prof Roy Spence		
HIV physician	Dr Quah		
Hepatologist	Dr Neil McDougall		
Obstetric / Gynaecology service / Surgeon	Mrs Anne Harper		
Paediatrician (in paediatric or paediatric/adult centre)	NA		
Dietician	Access as required		
Genetic Counselling Services	Dr Shane McKee		
Antenatal diagnosis arrangements	Dr Shane McKee		

COMMENTS
(Any contacts made with multidisciplinary staff during the visit should be noted)

The unit does not have the services of a data manager.
Although there is an in-patient ward physiotherapy service there is no out patient service at the City Hospital for haemophilia centre patients. Patients living outside Belfast can be referred to their local hospital for treatment. The centre is aware of patients that pay to have physiotherapy treatment privately.

The dental service provision is inadequate. Patients with acute dental problems will be seen at the dental hospital by Mr Mulally for treatment but there are too many patients to allow an effective routine follow up arrangement. There are some patients which have had no routine dental check ups for a number of years. Patients tend not to access a local dentist as community dental care is provided privately and NHS funded services are few. Attempts are being made by Dr Benson to establish a community dental care service for unit patients.
Orthopaedic services are provided at Musgrave Park Hospital. Referrals are made to the appropriate surgeon. Haemophilia nurses co-ordinate factor treatment for surgery.
Five patients are HIV infected. They are reviewed by Dr Benson and Dr Quah in a joint clinic on the unit held 3 monthly.
Twenty patients are HCV infected (3 co-infected). Half are managed by Dr McDougall at the Royal Victoria Hospital whereas the others prefer to be managed on the unit. Unit staff directly co-ordinate HCV combination therapy for these patients with the full support of Dr McDougall. If there are any concerns regarding the patients managed by the unit they are referred back to the Royal Victoria. The unit have completed a look back operation.

The social workers are shared with the haematology oncology service.
Mrs Marita McMullen provides a highly regarded and popular reflexology and aromatherapy sessions on the unit on Monday and Wednesday afternoons for both unit patients and their relatives.

The following were met by members of the audit team over lunch at the City Hospital

Mrs Ann Harper
Dr MacDougall
Jane Rankin, Lead Cancer Physiotherapist
Occupational Therapists
Social workers Una McGiven and Ann McClosky
Dr. David Robinson, Clinical Coordinator, Oncology/ Haematology Outpatient Services.
Reflexologist / Aromatherapist – Mrs Marita McMullen
Ms Gillian Traub - Haem / Onc business manager

5. PATIENT MEDICAL RECORDS REVIEW

Standard- The following should be present in the patient's medical records:

- clear documentation giving the diagnosis and usual treatment
- genetic mutation
- family pedigree with identification of obligate carriers / confirmed carriers
- appropriate review interval as per National Service Specification recommendation (six monthly for severe and moderate haemophilia, yearly for mild)
- appropriate physiotherapy / orthopaedic referral
- appropriate management of HIV, hepatitis B / hepatitis C infection as per national guidelines where applicable.
- evidence of effective communication with primary and secondary care colleagues and affiliated regional haemophilia centre directors.

It is recommended that a random sample of 8 medical records are reviewed.

5.1. There is documentation giving the patient's diagnosis:

Number of records with this information …..8

5.2. There is documentation giving the patient's usual treatment:

Number of records with this information …8..

5.3. There is clear documentation of the patient's vCJD at risk status

Number of records with this information …7..

5.4. There is documentation of the patient's genetic mutation:

Number of records with this information …5..

5.5. There is documentation of the family pedigree:

Number of records with this information …8..

5.6. There is evidence of appropriate follow up review:

Number of records showing this to be satisfactory….8.

5.7. There is evidence of appropriate physiotherapy / orthopaedic referral

Number of records showing this to be satisfactory….7.

5.8. There is evidence of regular dental review

Number of records showing this to be satisfactory…..0

5.9. There is evidence of appropriate management of HIV, HBV, HCV infection where applicable

Number of records showing this to be satisfactory….7.

5.10. There is evidence of effective communication with general practitioners and consultant colleagues

Number of records showing this to be satisfactory…8..

5.11. Investigation results are readily accessible in the medical records

Number of records showing this to be satisfactory…..8

COMMENTS

On the whole the medical records are excellent. Three records did not contain the patient's genetic mutation.

6. CLINICAL GOVERNANCE, AUDIT, TEACHING, CPD, RESEARCH.

Standard – There is evidence that CCC staff participate in clinical governance, audit and teaching activities. There is evidence that unit staff undergo regular personal performance review and participate in CPD schemes. The unit participates in clinical trials and active research.

6.1. CCC staff participate in clinical governance and audit activities:

YES

The unit participates in the clinical haematology audit meeting programme presenting audits 2 monthly.

Give a list of recent audits performed:

- Questionnaire sent to patients when Dr Benson started asking for opinions on service development preferences.
- Usage of Octoplex.
- Appropriateness of obstetric clinic referrals.
- Laboratory based audit of appropriateness of thrombophilia screen requests.

6.2. CCC staff participate in teaching activities:

YES

Give examples of teaching activities:

- Dr Benson involved in medical student / haematology SpR /nursing teaching
- Dr McNulty involved in medical student and midwives teaching.
- CNS McAfee teaches on the Trust haematology nurses course and also ward and day unit nurses

6.3. CCC staff undergo regular performance review:

YES

The haemophilia nurses now have regular staff development reviews with the manager of the haematology/oncology unit who is their line manager.

6.4. CCC staff participate in continuing professional development:

YES

Dr Benson participates in the RCPath CPD scheme

Dr McNulty and CNS McAfee participate in informal CPD

6.5. The unit participates in clinical trials:

YES

- Post marketing surveillance of rFVIIa usage
- Propact study of rFVIIa prophylaxis
- UK TTP registry

6.6. The unit participates in clinical research:

YES

- Predominantly on genetic mutations in bleeding disorders in conjunction with Dr Paul Winter

COMMENTS

7. THE HAEMOSTASIS LABORATORY FACILITIES

Standard – The haematology laboratory in which the CCC haemostasis laboratory is located should have full CPA accreditation. The haemostasis laboratory should be adequately staffed with an appropriate skill mix and have adequate space and facilities to perform an effective diagnostic and monitoring service. The laboratory should participate in a national quality assurance scheme. Clotting factor assays should be available throughout the 24 hour period.

7.1. The haematology laboratory has full CPA accreditation:

YES

If yes, year of last CPA inspection….2009

7.2. The staffing levels and skill mix is adequate to provide an effective service:

NO

7.3. The laboratory space and facilities are adequate:

YES

7.4. The laboratory participates in a national quality assurance scheme in coagulation:

YES

7.5. Has there been any persistent poor performance over the previous two years?

YES

If yes, list the problem assays

NEQAS Fibrinogen assay on main lab analyser, not an issue on haemostasis laboratory machine

7.6. The following tests are performed in the haemostasis laboratory:

	YES	NO
All coagulation factors	Tick	
FVIII Inhibitor screening	Tick	
FVIII Inhibitor quantification	Tick	
VWF antigen	Tick	
VWF activity	Tick	
VWF multimers		Tick
Platelet aggregometry	Tick	
PFA 100 analysis	Tick	
Platelet granular constituents		Tick

7.7. If any of the above tests are not performed outline the alternative testing arrangements.

vWF multimers sent to Edinburgh

7.8. List any diagnostic tests that are performed not listed above:

HIT ELISA
FXa heparin assay

7.9. Coagulation factor assays are always available throughout the 24 hour period: (Evidence of this must be provided)

YES

All BMLSs participating in the out of hours rota are trained in performance of factor assays.

7.10. A diagnostic genetic laboratory service is provided

YES

By Dr Paul Winter
CVS DNA analysis is sent to Edinburgh.

If yes, has the service been audited as part of the UKHCDO / Haemophilia Clinical Scientists audit scheme and is the audit report available for review?

YES

If no, what arrangements are in place?

COMMENTS

The staffing levels are not adequate for a regional haemostasis laboratory. There are three permanent senior staff members Pamela Murray, band 7, Peter Cooke, band 7 and a band 6 BMS who was away at the time of the audit. Mrs Murray participates in the laboratory out of hours so takes a day in lieu from the normal working week after on call.

8. PAEDIATRIC CARE IN CENTRES LOOKING AFTER CHILDREN

Standard – The care of children with haemophilia and related disorders can be complex and should only be carried out by staff who are experienced and trained in the management of children. Facilities should be adequate for the care of children.

Not Applicable

8.1. Staff qualifications

Medical staff -	YES	NO
Consultant Haematologist has paediatric training and expertise		
Consultant Paediatric Haematologist		
Named Consultant Paediatrician supporting Consultant haematologist (in centres without a Consultant Paediatric Haematologist)		
Consultant Paediatric Surgeon with experience of implantable venous access devices		
Nursing staff -		
Unit nursing staff have appropriate qualification eg Registered Sick Children's Nurse(s) (RSCN) RN Child Branch (Project 2000) BA Nursing (Child)		

COMMENTS

8.2. Treatment facilities and services

	ADEQUATE	INADEQUATE
Appropriate paediatric in-patient and out-patient facilities		
Child friendly waiting/play area and toys		
Child friendly treatment area		
Out of hours treatment facilities		
Paediatric resuscitation facilities		
Training in paediatric resuscitation		
Use of local anaesthetic creams and distraction techniques		
Effective outcome monitoring of patient on prophylaxis		
Appropriate transitional arrangements for the transfer of adolescents to adult services are in place		

COMMENTS

8.3. *General paediatric services

	ADEQUATE	INADEQUATE
Availability of trained / experienced physiotherapists		
Growth and development assessment programme		
Availability of play therapist		
Liaison with Health Visitors/School nurses		
Liaison with nurseries and schools		

** See also section 5 Availability of Comprehensive Care Services*

9. CLOSING MEETING BETWEEN AUDITORS AND CCC STAFF

9.1. List the issues raised at the previous audit and indicate whether or not they have been rectified.

- Appointment of a new director - achieved
- Clarification of Dr McNulty's position - ongoing negotiations
- Establishment of 'link nurses' system with haematology unit nurses to assist with unit haemophilia nursing – partially achieved but problems remain with availability of these nurses to attend the centre when most needed e.g. on clinic days.
- Upgrading of haemophilia CNS to band 7 – not achieved.
- Establishment of 'transitional care' arrangements with the children's unit – achieved.
- Appointment of a data manager – not achieved.
- Instalment of a data base system ideally HCIS – in house software package introduced but HCIS not purchased.
- Identification of a senior Trust manager and dialogue with commissioners to co-ordinate haemophilia issues – limited progress achieved.
- Update of unit protocols –achieved
- Increase in medical involvement in the haemostasis laboratory – achieved with appointment of Dr Benson
- Staffing review in haemostasis laboratory – not achieved
- Participation in clinical trials – achieved
- Development of business plan for physiotherapy input – ongoing
- Consideration of introduction of home delivery programme – not pursued because VAT is not charged on recombinant factor concentrates in NI so there would be no savings to offset against company delivery charges

9.2. If there are outstanding issues, what are these and what have been the barriers to resolving them?

The main barriers that have prevented resolution of the above issues appear to be lack of resource and identifiable senior managers within the Trust and at the NI health board level to take these issues to.

9.3. Issues identified during this audit meeting and mutually agreed provisional plans to address these.

- Serious consideration needs to be given to the establishment of a second consultant haemostasis and thrombosis post to partner Dr Benson to come into line with all other regional UK adult haemostasis and thrombosis centres. This will address the major clinical governance issue of cover for the service which is not acceptable at present.

- The importance of Dr McNulty's role and responsibilities on the unit has to be fully recognised with re-grading of her post to Associate Specialist
- It is inappropriate that CNS McAfee remains on a band 6 and is it imperative that her role and responsibilities are fully appreciated and reflected in the grading. To be in line with other haemophilia lead nursing posts in the UK this would be at least a band 7. Furthermore this is the only adult haemophilia specialist nursing post in Northern Ireland and therefore carries regional responsibilities for advice, policies and protocols, training and consultancy. The banding is the subject of an appeal which has only reached panel stage after two years. The need to move this forward was discussed on the audit day with the line manager, Dr David Robinson.
- Orientation and ongoing training should be structured for named link nurses and there should be explicit arrangements for their release for haemophilia nursing when required.
- The provision of dental services for adults with bleeding disorders is of grave concern despite the ongoing efforts of Dr Benson to improve liaison with the dental hospital service. It is recommended that a business plan is developed to establish dedicated sessions at the dental hospital for the unit patient cohort with an emphasis on restorative and preventative service provision.
- Out patient physiotherapy provision is sadly not available and it is vital that the proposed dedicated post covering the paediatric and adult units is established. This will enable a marked improvement in the quality of patient care. . This issue was discussed with Jane Rankin the Lead Cancer Physiotherapist who was keen to develop a dedicated post and utilise advice from specialist haemophilia physiotherapists at other UK comprehensive care centres. A Job Plan and Business Case have been revised.
- It is recommended that social work time is clearly dedicated to haemophilia rather than existing arrangements of cover from the haematology/oncology social work team. The social work needs of the service should be scoped in order to identify dedicated time and skill levels required.
- It is inappropriate that the centre clinical staff are having to perform data management tasks and it is highly recommended that a data manager is appointed to cover the paediatric and adult units and co-ordinate these duties across both sites.
- Data management requirements would be markedly improved with the introduction of HCIS.
- The regional haemostasis laboratory is woefully understaffed and an improvement in manpower with a skill mix review is essential. It is vital that the issue of succession planning is addressed.

10. SUMMARY OF AUDIT FINDINGS AND RECOMMENDATIONS

There has been a dramatic improvement in the quality of the service offered by the adult centre since the last audit following the appointment of Dr Gary Benson and all credit should go to him for what he has achieved in the relatively short period he has been in post. He is ably supported by Dr McNulty who is vastly experienced in haemophilia care and by an equally experienced and dedicated nursing team. Most comprehensive care elements are in place except for dental services and out patient physiotherapy input. Hepatitis C and HIV management appears to be of high quality and the obstetric liaison service is impressive. The reflexology service is also worthy of mention. Data management systems have improved but there remains the need for a data manager to optimise data capture and coordinate the National data base submissions.
The haemostasis laboratory although short staffed provides a high quality service and the excellent genetic analysis service provided by Dr Winter is to be highly commended.
There appears to be a high level of patient satisfaction apart from assessment and management of joint problems which hopefully will be addressed by the appointment of a dedicated physiotherapist.
The auditors recognise the great potential of the NI Comprehensive Care haemophilia unit and if the recommendations in this report are carried through the unit could become one of the very best in the UK.

Patient Questionnaires – 11 out of 20 distributed questionnaires were returned.

There were a number of commendations that were given:

- Duration of Appointments – much greater than that with GP, more time with the doctor at the Centre
- Medical Staff – many compliments including: very pleasant, dedicated, competent and personal, "perfected the art of caring"
- Facilities – very good compared to Royal Victoria

There were a number of areas of concern raised by the patients surveyed:

- Home Delivery – this feedback was in contradiction to the view held by the Centre that home delivery was not required or desired by patients. 7 out of 11 patients would like the option of home delivery and some mentioned they had not had home delivery discussed. 2 patients who suggested they already had it may be confusing home delivery with home treatment. A further 2 suggested they do not have a need for it. This is perhaps an area which could be discussed or surveyed further in order to more accurately assess patient opinion – although it is difficult to see how this could be easily achieved given the lack of VAT saving in N Ireland
- Joint Assessment – with a particular reference to the lack of a physical examination at routine appointments or the chance to see a physiotherapist with experience of haemophilia – 5 patients

- Expert Patient Programme – 5 patients had never heard of this scheme
- Dental Service – 2 patients commented on the lack of a dental service
- Hospital Transportation – 2 patients highlighted problems with the punctuality of the service
- Corridor Seating – 1 patient thought the seats in the corridor waiting area were uncomfortable and 1 patient said they were not suitable for children
- A + E Admission – 1 patient deemed this inappropriate where there was internal bleeding and/or infection
- Viral Load – 1 patient suggested written updates would be helpful
- Children's Play Area – 1 patient noted the lack of a play area for patient's children
- Opportunity to meet other families - 1 patient raised this as lacking

Dr J T Wilde
NC C Harrington
Mrs R Cooper
Mr M Gregory

January 2010