Ministerial Task and Finish Group on Haemophilia Services

Report and Recommendation arising from Review of services for people with inherited bleeding disorders - June 2011

Background

On the 8th March 2011, the previous Minister for Health and Social Services made a statement about the support available to individuals infected with hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependents. As a result of a commitment made during her statement, a Ministerial Task and Finish Group was established under the chairmanship of the Medical Director for NHS Wales to review services for people with inherited bleeding disorders.

A copy of the terms of reference and membership for the Group is attached at appendix 1. The Group was established in March 2011 and met three times. The Group considered a range of concerns raised by patient groups on the planning and delivery of diagnosis, treatment and support services, including physiotherapy, counselling and social services support, for people with inherited bleeding disorders in Wales.

Summary of patient concerns

A wide range of patients' concerns were raised with the Group who have sought to address as many of these as possible throughout this report.

1. Data Management

There is no consistent data management system throughout Wales to enable data to be inputted into the National Haemophilia database. This is only available at Cardiff Comprehensive Care Centre.

2. Diagnostics

There are significant concerns regarding availability and access to diagnostic services outside South Wales.

3. Treatment Programme/Expertise in the management of inhibitors

There is significant expertise within the Cardiff Haemophilia Centre to manage inhibitors and the treatment of women with bleeding disorders, but this level of service is not apparent in other parts of Wales. Patients with haemophilia who are on regular coagulation factor are not always regularly screened for inhibitors.

4. Home Treatment and Community nursing support

Outreach services to support patients to receive their treatment at home are only available to a limited number of patients in South Wales.

5. Play Specialists

There is little provision of, for example play specialists, to help alleviate anxiety in children and help them cope with the pain and fear associated with treatment.

6. Needs of women with bleeding disorders

There is an inequality of access to specialist treatment for women with bleeding disorders who specific needs at the time of child birth and related to menorrhagia.

Where there is no family history of bleeding disorders there is a risk that GPs do not refer women early enough to specialist advice.

7. Virally Infected and patients exposed to vCJD

There are problems with access to services for people suffering with HIV, Hepatitis C and those who have been designated as at risk for vCJD for public health purposes.

8. Clinical Support Services

Gaps in the provision of various Clinical Support Services are apparent. This is most significant with regard to the hepatology service at Cardiff and Vale University Health Board but there is also concern about counselling, social work and psychological support, physiotherapy, orthopaedics and rheumatology and dentistry.

9. Access to treatment centres

There are issues around access to treatment centres in relation to

Ambulance access
Re-admission
Out of hours cover
Access to disabled parking

A summary of patient experiences can be found at appendix 2, which highlights issues experienced by patients.

High level summary of current service provision

Number of Welsh patients with inherited bleeding disorders

Centre	All Bleeding Disorders	Haemophilia	Severe Haemophilia	HIV	HCV	At risk vCJD
Bangor	130	Haem A - 24 Haem B - 1	Haem A - 12	1	7	87
Liverpool (welsh patients)	56	Haem A - 14 Haem B - 4	Haem A – 5 Haem B - 1	2	3	9
Alder Hey	31	31	3	0	0	0
Cardiff	550	Haem A - 177 Haem B – 45	Haem A – 66 Haem B – 12	20	100	166

Source: Information provided by NHS Haemophilia centres

It is estimated that that approximately 300 of the patients with bleeding disorders are children.

Services in Wales for adults and children comprise the Arthur Bloom Comprehensive Care Haemophilia Centre (CCHC), based in Cardiff and Vale University Health Board, and two haemophilia centres based in Abertawe Bro-Morgannwg University Health Board and Betsi Cadwaladr University Health Board.

A description of the different level of care can be found in Annex 3. Services should be provided in line with the requirements set out in the Haemophilia Alliance National Service Specification for Haemophilia and Other Bleeding Disorders (2006).

North Wales

Within North Wales there is a Haemophilia Centre in Bangor and outreach clinics are provided twice a year by the Comprehensive Care Centre (CCC) in Liverpool at Glan Clwyd. In addition a number of paediatric patients with severe bleeding disorders receive treatment from Alder Hey Children's NHS Trust. As some patients live in rural parts of North Wales, many patients prefer to be managed locally rather than having to travel long distances for specialist care. However, it is important that they are able to access a comprehensive service that is equivalent to that offered in other centres in Wales.

The service in Bangor has 0.05 WTE consultant haematologist sessions a week. Support from physiotherapy, psychology and social work is available but not dedicated to patients with haemophilia which means that when required people with bleeding disorders must compete with all other referrals. The service as it exists is configured to adult health and a much improved liaison between this service and paediatrics is required to meet the needs of younger people with haemophilia. Out of hours service and surgical services are provided by District General Hospitals. The management of haemophilia patients can therefore be challenging out of hours in terms of accessing expertise. Surgical issues are managed often by referral to a comprehensive care centre.

A detailed description of the current service provision and action plan to improve services can be found at appendix 4.

Mid and South Wales

A networked service operates across South Wales. The Comprehensive Care Haemophilia Centre (CCHC), in Cardiff, is responsible for the care of all people with inherited bleeding disorders in South Wales and jointly manages a proportion of these patients with the haemophilia centre in Swansea. The Director of the CCHC in Cardiff has a monthly joint clinic with the Consultant Haematologist leading the haemophilia service in Swansea.

Some blood products are dispensed from other hospitals in South Wales (e.g. Withybush, Carmarthen or the Royal Gwent) and blood products are administered under the instruction of the Arthur Bloom CCHC and the haemophilia centre at ABM UHB.

The Arthur Bloom CCHC provides comprehensive services for patients with bleeding disorders in accordance with the standards described in the National Service Specification for Haemophilia and other Inherited Bleeding Disorders.

Accordingly patients with haemophilia have access to:

- 24 hour per day access to treatment advice from consultant haemophilia medical staff.
- A networked service encompassing neighbouring haemophilia centres and including shared care protocols and guidelines.
- Regular Multi Disciplinary Team meetings and out patient and joint out patient clinics with other key specialties (e.g. paediatrics, gynaecology and hepatology).
- Monthly outreach clinic at the haemophilia centre in Swansea.

- Physiotherapy and dental reviews, dietetic advice, as well as open access to orthopaedic clinics.
- Genetic counselling and mutation testing.
- Data collection and management.
- Comprehensive care for paediatrics.

A detailed description of the current service provision and a proposed model of future can be found at appendix 5.

Gaps identified by the Task and Finish Group

The main gaps in services identified by the Group were:

- Lack of counselling and social work support across Wales
- Lack of hepatology support particularly in Cardiff
- Lack of specialist physiotherapy input across Wales, apart from Cardiff
- Poor access to services, as close to home as possible, for patients especially from Powys, North and West Wales
- Potential inability to access appropriate diagnostic testing
- Lack of availability of appropriate NHS dentistry services

Summary of Findings

The effective management of patients with inherited bleeding disorders is complex and involves the provision of comprehensive care by a team of health care professionals with diverse skills.

The Review has identified a number of service gaps that need to be addressed. Priorities include addressing the service issues within North Wales, access to counselling and social work support, increasing hepatology input into the service in Cardiff and providing greater equity of access to services for patients in Mid and West Wales.

Recommendations

In order to address the concerns raised by patient groups and the gaps in service provision, the Task and Finish Group recommend that:

1. An All Wales multidisciplinary National Advisory Group with user and WHSCC representation should be established to share best practice, promote self-care, provide advice and assist in the planning/delivery of services for patients with inherited bleeding disorders.

2. LHBs, through their joint work on WHSSC should ensure that services in North Wales should be consolidated and strengthened in line with the actions set out in the North Wales action plan and for patients with severe bleeding disorders should be provided in conjunction with a Haemophilia Comprehensive Care Centre. Recommendations include:
   a. establishing a formal link with a comprehensive care centre
   b. establishing a multi-disciplinary approach
   c. developing guidelines for clinical practice
   d. identifying a model for 24 hour provision of expertise

These aims can only be achieved if there is an increase in specialist consultant haematologist sessions

3. LHBs, through their joint work on WHSSC should ensure that services in Mid and South Wales should be closer to the patients' homes in West Wales through strengthening the provision of out reach services from the centre in Swansea and in East Wales through establishing outreach services in Nevill Hall. The outreach service from Swansea to west Wales is dependent on the appointment of a consultant haematologist with a specialist interest in bleeding disorders by ABM from currently available resources.

4. LHBs, through their joint work on WHSSC should identify, as part of the annual WHSSC funding plan, how much money has been allocated to the provision of haemophilia services and to ensure that the money designated for haemophilia services is spent on providing services for patients with inherited bleeding disorders.

5. LHBs, through their joint work on WHSSC must provide appropriate resources to ensure information is submitted to the national haemophilia data system.

6. Patients with inherited bleeding disorders, particularly those listed as at risk of vCJD, should have access to appropriate diagnosis testing such as endoscopes when required.

7. LHBs, in collaboration with WHSSC, need to ensure that adequate succession planning is undertaken to ensure service sustainability and that the specialist skills developed by the small number of clinicians, nurses and physiotherapists who provide the service are not lost.

8. All Haemophilia Centres in Wales must have formal links to a Comprehensive Care Centre to ensure that all patients have access to services for more complex elements of care

9. Specialist Haemophilia Nursing:
   LHBs, through their joint work on WHSSC should
   a. Provide administrative support to allow the existing specialist nurse provision within Swansea to provide a service to patients from West Wales
   b. Extend access to patients in Mid and East Wales, through the appointment of a link nurse based in Nevill
   c. Ensure the haemophilia nurse post in Bangor is protected with appropriate cover provided for leave etc and a paediatric link established

10. LHBs, through their joint work on WHSSC must ensure that services for children and young people with bleeding disorders meet the requirements, particularly with regard to play specialists, set out in the All Wales Universal Standards for Children and Young People Specialised Healthcare Services and the National Service Framework for Children, Young People and Maternity Services in Wales.

11. LHBs, through their joint work on WHSSC should ensure that there are pathways in place to allow for early identification of patients, particularly women, who may be at risk of a bleeding disorder.

12. The Chief Executive of the NHS should write to Chief Executives of LHBs disseminating the Welsh Government response to the Equality Committee's inquiry into discrimination of people living with HIV and stating that these recommendations need to extend across to people living with hepatitis and at risk of vCJD. These recommendations should also be included in postgraduate medical education.

13. Physiotherapy services:
    LHBs, through their joint work on WHSSC should
    a. Establish a specialist physiotherapist post in Swansea, (based at Singleton Hospital) linked to Cardiff Comprehensive Care Haemophilia Centre for Continuing Professional Development (CPD) requirements
    b. Establish an Outreach clinic from the Swansea centre to be held at Withybush Hospital, where the Swansea specialist consultant and Physiotherapist could see patients from the wider area, reducing the need for them to travel to Cardiff or Swansea for reviews and treatment
    c. Ensure a named physiotherapist is identified in other hospitals such as Nevill Hall, Carmarthen, Withybush and Aberystwyth to whom referrals could be made and discussed
    d. Consider the provision of additional physiotherapy services to support the increasing workload within Cardiff and provide peer support; holiday and study leave cover and allow for more outreach work and succession planning
    e. Establish a dedicated specialist haemophilia physiotherapist post in order to provide the required standard of care for patients in North Wales

14. Counselling and Psychological Services:
    LHBs, through their joint work on WHSSC should
    a. Ensure that social work service currently available in the Cardiff Comprehensive Care Haemophilia Centre is secured and rendered less vulnerable to financial and workforce/workload fluctuations allowing the potential for greater outreach to West and Mid Wales
    b. Secure and strengthen paediatric psychology service
    c. Provide haemophilia centres with dedicated psychology input from a clinical health/paediatric psychologist in the host health board to facilitate effective team working and liaison with local services
    d. Ensure steps are taken to bring the North Wales service in line with the service available in South Wales. The LHB and its partner Local Authorities should address the provision of such a service to address the apparent current service gaps

15. Hepatology Services:

LHBs, through their joint work on WHSSC should

   a. Ensure appropriate consultant and specialist hepatology nurse input into the treatment of patients with inherited bleeding disorders must be provided in Cardiff

16. Dentistry Services:
    a. A clinical care pathway should be developed for patients with inherited bleeding disorders
    b. A Specialist in Special Care Dentistry to be responsible for all medically compromised patients
17. LHBs and the Welsh Ambulance Service need appropriate mechanisms to enable the early recognition of patients with bleeding disorders so they receive access to appropriate services and clinical staff can readily access a patient's medical history
18. LHBs should work together to identify a lead chief executive and establish two task and finish implementation groups, for North Wales and Mid and South Wales, to oversee the implementation of the recommendations of this Group.