

Ministerial Task and Finish Group on Haemophilia Services

Review of services for people with inherited bleeding disorders

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Appendix 1 - Terms of Reference and Membership

Terms of Reference

This review will consider services for those people with inherited bleeding disorders who have been infected with hepatitis C, HIV or at risk of vCJD as a result of contaminated blood, including access to counselling services. To review the process of planning and delivery of diagnosis, treatment and support services, including physiotherapy and social services support, for people with inherited bleeding disorders in Wales.

To submit a written report by end of May 2011 to the Welsh Government with recommendations on improvements to achieve optimal clinical outcomes and patient experience.

In fulfilling its terms of reference, the Task and Finish Group will take account of:

- Current relevant Welsh Government policy, service standards and care pathways

- Current work being undertaken by LHBs through their collective work on the Welsh Health Specialised Services Committee

- Current and forecast financial agenda

- Direction of travel by Welsh Government on setting and measuring clinical outcome and patient experience quality measures as a means of monitoring and performance managing the NHS

Membership

Chair – Dr Chris Jones, Medical Director for NHS Wales, Welsh Government

NHS Wales

Dr Peter Collins, Consultant Haematologist - Representative from the UK Haemophilia Centre Doctors Organisation (UKHCDO)

Dr Ruth Alcolado, Consultant Gastroenterologist - Representative from the Gastroenterology National Specialist Advisory Group (NSAG)

Christine Loran, Clinical Nurse Specialist – Nursing representative

Dr Geoffrey Carroll, Medical Director - Representative from Welsh Health Specialised Services Committee (WHSSC)

Dr Layla Jader, Consultant in Public Health - Representative from Public Health Wales NHS Trust

Fiona Hall, Specialist Physiotherapist - Representative from Welsh Therapies Advisory Committee

Dr Sarah Flowers, Consultant Clinical Psychologist - Representative from Applied Psychology National Specialist Advisory Group (APSAG)

Social Services

Rebecca Holland, Social Worker - Representative from Social Services

Service Users

Lynne Kelly, Trustee - Representative from Haemophilia Society
David Thomas - Patient Representative

Secretariat

Caroline Lewis - Adult and Children Health Branch, Medical Directorate,
Welsh Government

Co-opted members

Phil Chick, Mental Health Development Lead for Wales, NLIAH
Dr Karen Gully, Senior Medical Officer, Welsh Government
Dr Melinda Hamilton, Consultant Haematologist, Betsi Cadwaladr
University LHB
Mr Damian Heron, Associate Chief of Staff Operations & Planning -
Cancer, Palliative Medicine and Clinical Haematology, Betsi Cadwaladr
University LHB

Appendix 2 – Description of Haemophilia Care taken from Haemophilia Alliance National Service Specification for Haemophilia and Other Bleeding Disorders, 2006

Comprehensive Care Centres

A Comprehensive Care Haemophilia Centre (CCC) carries out the following functions and activities:

- co-ordination of the delivery of haemophilia services – both in hospital and in the community including liaison with affiliated Haemophilia Centres
- a 24 hour advisory and response service for patients, families, hospital doctors, general and dental practitioners and affiliated Haemophilia Centre health care professionals
- delivery of a comprehensive care programme for paediatric and / or adult patients with haemophilia and related conditions
- provision of coagulation factor concentrates both for hospital treatment and home therapy programmes including prophylactic therapy and home delivery of factor concentrate where appropriate
- home treatment training programmes including home and school visits where appropriate
- counselling for patients and their families including family support groups
- social work support and welfare advice
- physiotherapy
- general and specialist surgery
- an interventional and restorative dental service
- rheumatological and orthopaedic review service with provision of surgery where appropriate
- a specialised obstetric and gynaecological service for the management of haemophilia carriers and women with von Willebrand Disease and other hereditary bleeding disorders
- specialised services for patients with HIV and viral hepatitis
- a diagnostic and reference laboratory service providing a full repertoire of tests enabling the diagnosis and monitoring of inherited disorders of haemostasis
- a 24 hour laboratory service for clotting factor assays and inhibitor screens
- genetic counselling and diagnosis in conjunction with specialist genetic laboratories
- participation in clinical trials and research and development
- participation in clinical and laboratory audit and in their hospital's clinical governance programme
- participation in the national UKHCDO & HNA triennial CCC audit programme
- participation in educational programmes for medical and nursing staff, biomedical scientists and related health care staff
- provision of educational programmes for patients and their families concerning all aspects of haemophilia care.

Haemophilia centres

Expertise in Haemophilia Centres (HCs) varies widely. Some centres offer the majority of services that are provided by a CCC. At a minimum, a Haemophilia Centre must be able to provide the following:

- a 24 hour emergency treatment service for patients with haemophilia and other inherited bleeding disorders
- provision of home treatment programmes
- provision of appropriate clinical advice to patients and families
- provision of adequate supplies of factor concentrate for hospital and home treatment
- a 24 hour diagnostic and monitoring laboratory service for the more common inherited bleeding disorders either on site or by arrangement with their local CCC
- participation in clinical and laboratory audit and in their Trust's clinical governance programme.

Appendix 3 - Summary of Patient Experiences

1. Wife of a patient that died

Her husband died aged 44, after he received Contaminated Factor 8 when he was 14 years old.

The only Haemophilia Centres available in Wales are located at Cardiff, Swansea and Bangor and Haemophiliacs have 'Open Access' to the Haemophilia Centre and Haematology wards without having to be admitted through A and E at these locations. They do not have 'Open Access' at other hospitals and cannot receive the necessary Haemophilia treatment except at these centres. Haemophiliacs do not have 'Open Access' at any hospital to any other Clinical Department.

She explains that the problem of 'Open Access' is when Haemophiliacs develop complications through Hepatitis C or more commonly when they require other clinical interventions as a result of the contaminated blood issue, 'Open Access' is denied. The Haemophilia Centre can only admit patients onto a Haematology Ward, but not a Gastroenterology Ward which is where they need to be for specialist procedures. Her husband spent up to 12 hours on a trolley, in a corridor awaiting formal admission for procedures. During this time nurses would openly discuss the fact that he had Hepatitis C in front of other patients. On one occasion a nurse called to another nurse ' Make sure you have gloves on as he has Hep C'. She felt as if the Haemophilia and the way in which her husband was given the Hepatitis C through contaminated blood was ignored and whatever training nurses are being given, staff were unaware of the distinction between this and drug abuse.

When he was carrying a lot of fluid he could not fit in to a car, he often needed up to 7 stones of fluid draining from him. If an ambulance was called they would insist on taking him to the local district general hospital where there is no Haemophilia Centre. This would mean he could not be drained, as he would need factor 8 for this procedure. There were many times during the last year when an ambulance would arrive and then they would not take him to UHW Cardiff. They had to travel to Birmingham many times for consultations. The journey was difficult because of the fluid her husband was carrying. They had to borrow their cousin's estate car as he could not fit into their car.

It was discovered that her husband needed a liver transplant as by the time the necessary tests were done, he had a tumour outside the liver. The couple had to pay privately for a Triple Phase Scan and Transjugular Biopsy at the London Clinic.

She refers to the written statement by Edwina Hart which says the Welsh Government is committed to ensuring that people with Haemophilia and others who have been infected with Hep C or HIV from blood or blood products are well cared for, supported in their communities and fully informed on how best to look after their health. Any recommendations from the Haemophilia Alliance to improve the care of this patient group will be considered.'

She believes that this aspiration is a long way from reality:

“People assume that since the Announcement in March that we have received compensation. The truth is my husband’s life has been halved through NHS treatment, I have 2 daughters to support and the cost of his life is a mere £25,000. I do not think this compensation goes anywhere near to addressing the problem.”

2. Patient with a bleeding disorder

She refers to points raised with Cardiff CHC in 2001 by the Haemophilia Society:

“Orthopaedic services for haemophilia are poor and surgery has to be carried out at Llandough. The waiting list in Cardiff is far too long. This specifically disadvantages people with disorders that lead to joint damage.

Unlike other hospital departments Haemophilia Centres look after children. Trusts need to ensure proper services, facilities and staff are provided for their care.

There is a need for a structured genetic service. Future plans include 6-7 centre throughout the country that will perform all genetics in the UK. It is essential to ensure at least one of these centres will be in Wales otherwise we are in danger of being left behind England.”

She goes on to say that ‘we are in desperate need of more professional and able social work care, along with trained councilors who can deal with all aspects of haemophilia care. Haemophilia is a life long disorder, which affects the whole family. To be effective the social worker needs to fully understand haemophilia and the lifestyle and problems that it brings with it. Added to this the devastating effects of HIV and Hepatitis C and now the added worry of CJD we can think of no other disorder, which requires dedicated social care input.

3. Anonymous

One person has wrote a list of names of 21 people who were treated at the Haemophilia Centre in Cardiff who have died from contaminated NHS blood products.

4. Mother of an 18 year old son with severe haemophilia

Her 18 years old son has severe Haemophilia A and they attend Alaw Unit, Ysbyty Gwynedd, Bangor.

Her son is on prophylaxis daily at the moment as he is suffering with recurrent calf muscle bleeds. He has to be referred to a specialist Haemophilia Physiotherapist as there isn't one at Bangor, this can take about 6 weeks and when he was seen about a year ago he was promised a follow up appointment but this hasn't happened.

Her son requires more prophylaxis as he is not getting the appropriate Physiotherapy.

Her son is treated on Alaw Ward which is a Haematology and Oncology Ward. His mother feels it is inappropriate for Haemophilia patients to be treated with malignant Haematology patients as both needs are very different. There is also no counselling available to Haemophilia patients or their families.

When he was younger he had 2 portacaths fitted at Alder Hey Hospital, Liverpool. When they were at the hospital they were advised by the Social Worker that they were entitled to the Disability Living Allowance. They received this until Jonathan was 10 years old and then it was stopped. There isn't a Social worker at Bangor and they haven't had any advice on what would be available to them. They have never applied for a Disabled Parking Badge and there are no dedicated Haemophilia Parking spaces at the Hospital.

Her son is seen at a regular Dentist for check ups. He needs a filling at the moment and is then referred to a clinic in Penygroes which takes a year for the consultation appointment and then a further appointment for the filling to be arranged. This time lapse means that further complications can develop whilst waiting for treatment.

5. Mother of a 17 year old son with severe haemophilia

A Mother refers to the case of his 17 years old son who is a severe Haemophiliac. Her son is on prophylaxis 3 times a week and is on home treatment. She did not know that there was a chance that she was a Haemophilia carrier her sister's son was born with Haemophilia in 1989.

Her son is treated at Alaw unit, Ysbyty Gwynedd, Bangor which is a Haematology and Oncology ward.

When her son was younger he would usually be treated on the Children's ward. This was particularly problematic at weekends and during out of hours as there would never be a Consultant on call who knew anything about Haemophilia. Her son found this particularly distressing and it did not instill the family with any confidence when he was first diagnosed. They would wait for hours on end for their son to be treated whilst his bleed got worse. Her son's chubby arms made treatment very difficult, particularly when inexperienced staff try to access veins, he would have to be held down while different members of staff tried to find a vein. The whole experience was horrendous and has left a lasting impression on the family. As she had 2 sisters with sons who have Haemophilia, she was able to gain some support from them and she says she can't imagine how much worse it would be if there was no one else she knew who had had similar experiences. She has never been offered counselling or social work support.

When her son has knee joint bleeds he has been referred to a specialist Haemophilia Physiotherapist in Alder Hey but he cannot access a

Physiotherapist at Ysbyty Gwynedd. Her son's portacath was also fitted at Alder Hey. With regard to Dental Treatment her son is seen by a local dentist but has always needed to be referred to Ysbyty Gwynedd for extractions.

6. Parent of a son with a bleeding disorder

My son is currently being treated through the Swansea centre which is under resourced. We have one nurse and one Consultant, who I understand divides his time between clinical practice and lectures.

There is no waiting room and when there are routine appointments we all have to line up in the corridor for the world to see. There is no confidentiality about the process.

Because there are no registrars available this leads to having to turn up for urgent appointments subject to when the Consultant is available to see us.

There is no dedicated parking place for patients and this adds to the stress of having to drive around the hospital for parking places in a crises.

We are fortunate in that we do get to see the Cardiff team from time to time.

I have also found it difficult dealing with other Consultants who have little understanding of the condition. One dental consultant had the temerity to ask whether my son was viral checked before treatment.

As for holistic care I feel there is a lack of social care/ counseling available for patients and their families to deal with the stresses of the condition.

I have never been offered bereavement counselling for losing my brother to HIV and Hep C and I would hope that is something that will be addressed for all those who will have to face up to their loss from her on in.

If you look at the BBC Wales website you will see what upset they have caused the patients who were advised that there may be a risk of vCJD following surgery with the implements that were not properly sterilised and how they are now being counselled

I received a letter last year wrongly addressed to my son and not me as his parent advising him he was theoretically at risk of vCJD. He opened it. Nobody offered us counselling at the time and just expected us to take it in our stride. I feel that there is a lack of emotional and moral support certainly in West Wales.

7. Patient with bleeding disorder

In the past dentistry has been a concern. He had difficulty in finding any external dentist willing to take him on and at that time (some five or six years ago) he had experienced extreme difficulty in obtaining treatment in the Dental Hospital. In recent years things have improved. He is currently on an extended series of dental treatments for root canal fillings etc.

He says the main trouble lies in getting proper emergency dental treatment should you require it. Last autumn he had an abscess developing under his front teeth - the Unit gave him antibiotics to suppress the infection, but despite them ringing the dental hospital directly it was still about a month before he could get an appointment. His current series of treatments stems from that problem.

He says that he is happy with the physiotherapy he receives particularly the hydrotherapy sessions which have helped him quite a bit.

Overall, he feels the treatment in the Unit has been good. He goes to them for most of his general as well as purely haemophilia needs. He rarely goes to his local surgery where he sees different doctors each time, they find they have little idea of what to do for him. He finds that because the doctors on the unit are specialist haematologists he has to be careful. He recently had an infection (a sort of bad cough and cold) for several months. The Unit said his chest was clear, and only after pressure from him, did they take a sample and found he had indeed got an infection, which after treatment with antibiotics cleared up in about a week.

He has raised concerns with the Haemophilia Society over what will happen to his wife when he dies. She only has a small retirement pension and, as she has cared for him for so long, she has not worked and has no professional pension. His pension, is not large and she will only get half of that when he dies.

8. Patient with bleeding disorder

He is satisfied with the treatment he has received in the Haemophilia Centre however he says that physiotherapy spaced out over several days between treatments as an out patient can have its problems. He feels that frequent intensive physio over a short period is preferable to infrequent treatments over a long period.

He is happy with his dental treatment as he has regular check-ups and treatment at the Dental Hospital. He did not know other haemophiliacs were having to seek treatment outside of the NHS. He says that back in the 1960s it was emphasised that haemophiliacs should be regularly checked so as to avoid more drastic treatments leading to prolonged bleeding. He raises the concern about private dentists needing to give a 'block' injection without cover or an extraction.

9. Anonymous

One gentleman states that he has given talks to the Blood Transfusion Service on 9 occasions and written an article for the Genetics and Nursing Department of Glamorgan University which has recently been published on the Internet under a fictitious name. He restricted his experience to Haemophilia only, deliberately leaving out his personal experience with Hepatitis C. He states that it is surprising the ignorance that abounds regarding Hep C, HIV and vCJD.

10. Anonymous

One person comments on his shock at his well educated friend, people at his children's school, neighbours and local counsellors ill educated comments about haemophilia, HIV and hepatitis C.

He comments that luckily, he did not get infected with HIV, but he has been exposed to vCJD having received blood products from a blood donor who has since died of vCJD.

He comments that whilst not relevant to Hep C, to illustrate the ignorance that still prevail regarding people with disabilities or certain types of illness, a neighbour once asked his wife what work he did. When she replied, the neighbour commented, "Oh, he's fairly intelligent considering." He once over heard a comment that Haemophilia was caused by incestuous relationships in the family.

The only people who know about his hep C status are his wife, medical staff treating him, some older patients he has known since the 1950s, his MP, Assembly Member and the respective Ministers of Health who he have written to over the last 11 years campaigning for compensation."

Appendix 4 – Summary of service provision and action plan for North Wales

CANCER, PALLIATIVE CARE and CLINICAL HAEMATOLOGY CLINICAL PROGRAMME GROUP

Haemophilia Plan 2011-2014

Introduction

It is clear that for North Wales to sustain a Haemophilia centre more work is required to meet the National Service Specification for Haemophilia and other inherited bleeding disorders. This plan aims to describe the steps required to develop a sustainable service in line with the national standards. It is important to note it is the view of the lead clinician and lead managers that North Wales does not have sufficient patient numbers or specialist support to sustain a comprehensive care centre, but a centre in North Wales should form a regional Network with a recognised comprehensive centre.

Current services

The Haemophilia Centre in Bangor provides care for patients with bleeding disorders in Northwest Wales (Gwynedd and Anglesey). The number of patients in other parts of North Wales (covered by Ysbyty Glan Clwyd and Ysbyty Wrexham Maelor) is small and these patients are seen either in Liverpool or by a visiting Haematologist from that team. Haemophilia services are provided within the Cancer, Haematology and Palliative Care Clinical Program Group (Cancer CPG) of the Betsi Cadwaladr University Health Board (BCUHB).

Given the remote location of the area, these patients are 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 is led by a Consultant Haematologist with a limited number of sessions dedicated to bleeding disorders, the consultant is one of a team of approx 2.8 w.t.e in that location and they are supported by junior medical staff. In addition there is approx 0.8 w.t.e Clinical Nurse Specialist who is currently on maternity leave (she is being backfilled with a post at band 5, approx 0.6 w.t.e) . The location of care is the Alaw Unit within Ysbyty Gwynedd and this unit provides both inpatient, day case and out patient services.

The service is integrated within the general haematology service within Ysbyty Gwynedd which in turn is co-located with the local oncology/cancer service. As a result the medical and support team provide management of these patients against a context of far greater numbers of patients with malignancy. This model also applies to the environment which is dominated by the management of cancer.

Support from physiotherapy, psychology and social work is available but not dedicated to patients with haemophilia which means access is required to compete with all other referrals. The service as it exists is configured to adult health and liaison between this service and paediatrics is required when younger haemophiliacs arise.

Out of hours service and surgical services are those of a District General Hospital and thus management can be challenging out of hours in terms of accessing expertise. Surgical issues are managed often by referral to a comprehensive care centre.

Hepatology

Patients with inherited bleeding disorders who have hepatitis are referred to a Consultant Gastroenterologist for management and treatment of liver disease. The Bangor service has 7 patients with Hepatitis C. On-going monitoring is undertaken in the Haemophilia clinic. One patient travels to Cardiff for review in the joint hepatology clinic. Unfortunately, we are unable to undertake Ultrasound scan monitoring of these patients, for evidence of cirrhosis or hepatocellular carcinoma, due to lack of resources in the radiology department.

HIV Services

Patients are referred to the HIV specialist unit for advice and management. The HIV unit is part of Mersey, Cheshire and North Wales HIV managed clinical network and hence patients have access to regional expert specialist input from Liverpool. There is one full time HIV Physician and a dedicated HIV specialist nurse providing care including home delivery of HIV drugs.

Social care for HIV patients is provided by the voluntary sector. The Terrence Higgins Trust (THT) Cymru fund a dedicated client support worker based in the HIV clinic. This worker also has the remit to provide Hepatitis C social care.

Counselling and Clinical Psychology services (discussed above) is a major area of need for these patients who have complex psychological issues related to Haemophilia, HIV and Hep B/C infections. Deficiencies in these services impact greatly on these patients.

Activity

Bangor report 130 patients registered with their service of which 12 of 24 haemophiliacs are severe.

Liverpool report 56 patient registered with them of whom 6 have severe haemophilia – including 5 with severe haemophilia A and one with severe haemophilia B. Amongst the total group of registrants 14 have haemophilia A and 4 have haemophilia B. The remainder have von Willebrand's disease, platelet function defects and other less frequently occurring disorders of haemostasis.

Wrexham reports 50 patients with bleeding disorders, of whom 2 with severe haemophilia are seen in Liverpool.

Investigation with Manchester Royal Infirmary (Dr W Hay) confirms that the activity at Liverpool comes from both Glan Clwyd and Wrexham and that any referrals to Manchester are from the Bangor centre.

Issue	Detail	Objectives	Timescale	Resource Implications
Establish formal relationship with single local Comprehensive Care Centre (CCC).	Bangor needs to remain as a designated centre but needs to formalise links with an established CCC. These links need to be used for referral of complex cases, access to specialised surgery, clinical trials and audit.	Establish clinical links Agree criteria for referral Agree communication links Identify and agree any out reach commitments (possible transfer of visits to YGC)	Aug 2011.	Limited
Create MDT approach within Ysbyty Gwynedd.	Wider multi disciplinary team structure needs to be established within Bangor and this approach to the management of patients adopted.	Identify MDT members Identify clinical structure to support patient care Create SOP for function of the MDT	Sept 2011.	See below MDT should maximise use of Welsh VC service and use this technology to perform patient consultation with patients at peripheral locations inc North Powys.
Identify key MDT personnel and ensure that they have dedicated time to the provision of the service. Links to paediatrics need to be strengthened with a view to ensuring that the clinical care regarding the disease process is to the same standard as in adults.	Key personnel need to be identified and their time secured to ensure the service provided is both adequate and sustainable. In particular need to identify Medical staff Nursing support Physiotherapy Psycho/social support Data management and coordination Paediatric link member	Assess and then increase medical sessions into the service (may link into wider review of haematology services)* Ensure nursing support is maintained as a 1 w.t.e. Establish cover arrangements for CNS when she is on leave. Identify 0.4 w.t.e physiotherapy hours with support.	Sept 2011 Current Sept 2011	£50k p.a will fund additional sessions part of which are required to lead the development of the service. See below £25k required for dedicated sessions in support of assessment clinics.

	Social work	Identify psycho/social support and seek to maintain current cancer services in support of haemophilia patients (may link into wider review of haematology services)	Dec 2011	£45k p.a. from 2012. Current cancer psychology post could see these patients but funding expires in 2012. Requires dialogue with Mental Health CPG.
		Commit to plans for data/admin support.	Current	£ 30k to provide back fill for staff allocated to provide support
		Work with Children's CPG to create paediatric link nurse ensuring that they become an MDT member providing education in the clinical issues for paediatric services.	Dec 2011	£ 45k required to appoint nurse – post will also provide cover for adult services CNS and vice -versa (above). Post will be employed within Haematology and in reach into paediatrics.
		Establish 3 days of social worker time to provide access for patients including home visits	March 2012	£25k would also allow home access for patients from North Powys as they arise
		Identify additional hours of specialised dentistry ensuring that there is a North Wales tertiary service for dentals assessment and intervention as required	March 2012.	£25k would add support to the current single handed specialist dentist in BCUHB and benefits would be realised in other disease groups.

				Additional posts both medical and nursing will facilitate home/community visits thus accommodating patients from N. Powys.
Identify model of care regarding assessment and follow-up	Having established a link with a CCC and formed an MDT, a model of care needs to be established regarding the delivery of assessment/treatment of new patients as well as follow up and management of current patients.	Establish SOP in support of model of care Assess model of care once established ensuring that care can be delivered in line with SOP. Explore patient feedback to ensure care model is in line with patient expectations	Nov 2011	Nil
Establish guidelines for clinical practice	The model of care needs to be supported by clinical protocols especially regarding the use of blood products and the ongoing assessment of patients for complications of their illness e.g. regular physio assessment	Establish what clinical guidelines are currently in use Validate current clinical guidelines for efficacy Create new guidelines for elements of clinical care being developed as part of this plan	Oct 2011	Nil
Establish guidelines for management of clinical care out of hours	Need to ensure that services across North Wales, and specifically within Bangor, are able to address the needs of patients with blood disorders as an emergency. This will need to concentrate on A+E departments, medical assessment units and primary care.	Identify routes of access to care out of hours. Agree common causes for out of hours access Describe optimum pathways and guidelines for care out of hours. Identify marketing approach for the circulation of guidelines across BCUHB and	Nov 2011	Nil

	Advice and education should reflect appropriate immediate local care and access to the required expertise.	primary care.		
Identify model of care for 24hr provision of expertise	<p>Model of care needs to be established in the knowledge that it will impact upon other non specialist services across BCUHB.</p> <p>These services need to have access to information and knowledge that ensures they manage these patients appropriately and where indicated are able to access optimum advice for the further management of these patients</p>	<p>Identify optimum model of care for out of hours provision*</p> <p>Work with relevant clinicians and CPGs to investigate impact of model and developments required to deliver the model*</p> <p>Support introduction of model of care with required education material for clinical staff and patients alike.</p> <p>Establish as part of this approach share care agreement with paediatrics.</p>	Dec 2011	Possible resource implications yet to be identified.
Educate patients in the need to inform health care services of their condition and provide information for them regarding access and information routes.	<p>Patients need to be informed of their disease and the risk factors associated with it.</p> <p>Patients need a clear understanding of the model of care provided locally and how they can access staff both in and out of normal hours</p>	<p>Establish what educational material is currently offered to patients.</p> <p>Update information in line with service developments</p>	Dec2011	Nil
Ensure laboratory support is adequate on 24hr basis.	Appropriate laboratory support is required at all times to support the analysis of tests and provision of appropriate blood products in sufficient volume	Scope current laboratory support and ensure Pathology CPG plans support access to adequate laboratory support 24hrs on all sites.	Jun 2011	Thought to be nil but depends on evidence
Repatriate cases from Comprehensive Care Centres in the North West.	Whilst some cases might need to remain with a CCC it is clearly the case that cases from the central and east	Identify contacts at Liverpool and establish clinical links	March 2012	Resources released form contract with RLI ?

	<p>teams are referred to Liverpool.</p> <p>This trend in unnecessary and undermines the viability of a centre in North Wales.</p>	<p>Confirm current numbers registered and degree of complexity of those patients. Establish business case to repatriate patients ensuring that services within North Wales can sustain increased numbers.</p> <p>Ensure all clinical teams within North Wales are aware of the need to refer to the Bangor centre in the first instance.</p>		
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* The development of an improved haemophilia service has been confirmed as a priority through the Review of Haematology being undertaken by BCUHB however this priority needs to be considered alongside other issues within the review and as such some developments e.g. increased medical manpower and out of hours access will need to reflect the wider developments in haematology.

It is also noted that the a number of issues rest with paediatrics and this add complexity to resolution of some of the issues identified i.e. tertiary paediatrics is provided by Alder Hey.

Repatriation

The context for this plan is the potential for repatriation of patients from the service in Liverpool. Although it is difficult to assess numbers as some patients will be complex in nature and legitimately under the care of a comprehensive haemophilia centre other it would seem attend Liverpool simply on the basis of historical referral practices.

It may be therefore that the suggested investment identified within this plan of £ 215k may ultimately be off set by a reduction in contractual value with Liverpool.

Appendix 5 - Summary of service provision and plan for Mid & South Wales

Outline of current services for inherited bleeding disorders in south and west Wales

The service is organised according to DGM (93) 100 and National Service Specification for Haemophilia and other Inherited Bleeding Disorders

Service providers

The service is organised as a network co-ordinated by the Comprehensive Care Centre (CCC) in Cardiff. Shared care of patients is established with the Haemophilia Centre at Singleton.

Cardiff: Comprehensive care centre based at University Hospital of Wales
Manages 100 patients with severe haemophilia or von Willebrand disease
Swansea: Haemophilia Centre based at Singleton
Manages 12 patients with severe haemophilia jointly with CCC
Newport: Haemophilia Centre based at Royal Gwent
Manages no patients with severe haemophilia

Patients also seen on an intermittent basis at Withybush, Carmarthen, Aberystwyth and Brecon

Staff

Comprehensive Care Centre in Cardiff

2.6 WTE consultants cover haemostasis and thrombosis of which 1.5 WTE is for inherited bleeding disorders and 1.1 WTE to cover other disorders. Out of hours there is a 1 in 3 rota.

1 WTE nurse manager for haemophilia centre
1 WTE paediatric clinical nurse specialist
1 WTE haemophilia nurse
1 WTE research nurse
1 WTE social worker
1 WTE physiotherapist
0.4 WTE play specialist
1 WTE data manager and 1 WTE clerical assistant

Haemophilia Centre in Swansea

WTE consultant
WTE nurse to provide bleeding disorder service and INR service

Access to services

Walk-in service for acute problems provided at Cardiff and Swansea

Out-patient clinics:

Cardiff 3 bleeding disorder clinics per week
Specialist bleeding disorder clinics in Cardiff:

- o joint clinic with paediatricians once a month,

- joint clinic with gynaecologist once a month,
 - joint clinic with liver specialist 3 times a year
 - Joint clinic with obstetricians once a week
- Swansea 2 clinics per month including one outreach clinic a month performed by a consultant from CCC

Management of inherited bleeding disorders

Bleeding episodes

Most patients are established on home treatment with telephone advice from Cardiff and Swansea. Patients attend centres at Cardiff and Swansea with more complex bleeds for review.

Prophylaxis

Co-ordinated by CCC and delivered through Cardiff and Swansea, includes home visits by haemophilia nurses.

Treatment of inhibitors

All care for patients with severe haemophilia and inhibitors delivered by CCC in Cardiff. The management of inhibitors is the most complex clinical problem in this cohort of patients and by far the most expensive. Cardiff is a referral centre for south west England for complex inhibitor patients.

Community support

Home and school visits provided by nursing staff.

Management of children

In Cardiff children are managed by CCC and paediatricians. Patients admitted under paediatrics are jointly managed with haemophilia centre staff. Portacath insertion performed by paediatric surgeons although some complex cases referred to Great Ormond Street for interventional radiology central line insertion. Paediatric MDT held once a month with paediatricians, haemophilia centre staff and family psychologist. Joint clinic held once a month. Service supported by one paediatric trained clinical nurse specialist and 0.4 WTE play specialist.

In Swansea out of hours children are seen and treated on a paediatric ward.

Psychology

Family psychologist attends monthly paediatric MDT to advise and also sees some cases but is not funded to perform this service.

No adult psychology service.

No service available outside Cardiff.

Social work

1 WTE in Cardiff and are asked to prioritise people with transfusion transmitted diseases. Since September 2009 this post is increasingly being used to provide social work support for other UHW patients with HIV and HCV which is restricting the workers availability to provide the social work service for people with bleeding disorders. The social workers provide the counselling service.

Only Cardiff CCC has a dedicated specialist social work service.

Physiotherapy

1 WTE physiotherapist manages the musculoskeletal complications of bleeding. Coordinates orthopaedic referrals and post operative rehabilitation. Undertakes musculoskeletal surveillance for all patients with severe haemophilia including children. Weekly hydrotherapy session in Cardiff.

Cardiff physiotherapist attends Swansea one day a month, otherwise Swansea patients travel to Cardiff to be seen.

Orthopaedic service

Strong links with named orthopaedic surgeons. Direct access to orthopaedic clinics at UHW for acute problems. Operations performed at Llandough.

Patients from Swansea travel to Cardiff for opinions and operations.

Interventional radiology

Embolisation of bleeding vessels performed at UHW.

HIV service

Cardiff patients are followed up through CCC and seen every 1-3 months. If viral load is detectable or any complications noted patients are seen within a few days by infectious disease team. Open access to HIV specialist pharmacist and dietician. All treatment changes directed by infectious disease team and managed jointly with haemophilia centre.

Swansea patients followed up through infectious disease clinic without involvement of haemophilia centre.

Hepatitis service

Cardiff patients followed up and managed by haemophilia service. Routine surveillance of liver function and complications of HCV performed through haemophilia clinics. Treatment to eradicate HCV performed and managed by haemophilia centre.

Joint clinic with liver specialist twice a year. Surveillance for varices and advice on chronic liver disease provided through this clinic.

Progressed liver disease presents to haemophilia centre and admitted to haematology ward. Limited access to specialist hepatology opinions and so gastroenterology opinions sought for advice on management. Advice sought by haemophilia directly from liver centre in Birmingham in some patients.

Patients referred to Birmingham for hepatocellular carcinoma or if liver transplant considered.

In Swansea patients are managed through liver clinics.

Service for patients at risk of vCJD for public health purposes

Patients followed up and counselled by haemophilia team.

The need to quarantine instruments that have been used for some invasive procedures, as directed by SEAC and HPA, interferes with normal management and results in patients receiving treatment that differs from other patients.

The introduction of a vCJD test will be a very difficult time for the patients involved and overwhelm the ability of haemophilia service to provide adequate counselling and psychological support.

Women with bleeding disorders

Joint bleeding disorder gynaecology clinic held once a month.

Pregnancies managed through weekly joint obstetric haematology clinic. Joint obstetric and haematology care whilst in labour for management of both mother and neonate.

Genetics service

Genetic education and family tracing performed through haemophilia centres in Cardiff and Swansea. If genetic counselling is required individuals and families referred to medical genetics in Cardiff.

Genetic testing performed in Cardiff supported by a clinical scientist funded by WHSSC.

Out of hours service

Cardiff: patients seen by haematology SpR with specialist consultant cover on a 1:3 rota. Some complex patients have direct access to consultants. Children managed jointly with paediatricians.

Swansea: patients managed by haematology consultant with access to advice from specialist consultants in Cardiff.

Outline proposal for a South and West Wales Bleeding Disorder Network

This proposal is a response the Task and Finish Group on Haemophilia established by the Welsh Government. It aims to improve access to Comprehensive Care for bleeding disorders and to bring services closer to patients. The standards are defined in the DGM (93) 100 and National Service Specification for Haemophilia and other Inherited Bleeding Disorders (2006).

The plan is to establish a network based on a hub and spoke model with the Comprehensive Care Centre (CCC) in Cardiff acting as the hub.

Proposals

1. Move the focus of care in south east Wales from the Royal Gwent to Nevill Hall
 - a. A joint outreach clinic attended by a consultant from Cardiff and a consultant at Nevill Hall will be established
 - b. Patients from mid and east Wales who currently attend Cardiff will be repatriated to Nevill Hall for routine follow up
 - c. The outreach clinic will be attended by a specialist physiotherapist from Cardiff who will build up links with a local physiotherapist
2. Build up the haemophilia centre at Singleton as a focus for west Wales

- a. Appoint a consultant with a special interest in haemostasis and thrombosis with resources that are currently available. The consultant will spend one session a week at the CCC in Cardiff to ensure continuing professional development to a standard appropriate for Comprehensive Care
 - b. The monthly outreach clinic from Cardiff to Singleton with a consultant and specialist physiotherapist will continue to support the service in Swansea
 - c. Patients will be repatriated from Cardiff to Singleton for routine follow up and as this practice is built up the number of clinics will increase
 - d. A named physiotherapist at Singleton will develop specialist skills in bleeding disorders under the supervision of the physiotherapist from the CCC. This will involve working jointly on outreach clinic days, attending the CCC in Cardiff and managing patients in Singleton between clinics
3. Outreach clinics to west Wales
- a. The haemostasis specialist in Singleton will establish outreach clinics in Withybush at a frequency dependent of patients' needs. This clinic will be run jointly with a local haematologist to build up local expertise.
 - b. The physiotherapist in Singleton will attend the outreach clinics and build up links with local physiotherapists.
4. Data management will be centralised, co-ordinated by the CCC and shared with the Haemophilia Centre in Swansea, Nevill Hall and Withybush in relation to:
- a. Outcome monitoring
 - b. Concentrate usage and financial oversight
5. Access to the Comprehensive Care Multidisciplinary team will be enhanced through the network
- a. Haemophilia nurse specialists
 - b. Paediatric nursing expertise
 - c. Social work support and counselling
 - d. Psychological support
 - e. Play specialist

6. An all Wales multidisciplinary bleeding disorder group, that includes user representatives and WHSCC, will be established

Resources required to establish network and improve local access

Release of available funds to appoint specialist consultant at Singleton

0.5 WTE physiotherapist at Singleton

Clerical assistance in Singleton to support expanded clinics both locally and in west Wales and support home delivery of concentrate

0.5 WTE haemophilia liaison nurse at Nevill Hall

Second physiotherapy post in Cardiff to ensure sustainability and release current specialist physiotherapist for more outreach work

Ring fence the 1 WTE social work post to work exclusively with bleeding disorder patients

Family psychology service 0.4 WTE

Adult psychology service 0.4 WTE

Clerical assistant 1 WTE at CCC to work with data manager to co-ordinate integrated data collection, outcome monitoring and financial oversight throughout south, mid and west Wales

Appendix 6 - Provision of Haemophilia Nursing

The role of the Haemophilia nurse

Provision of experienced and trained nurses is essential for the delivery of a quality service to patients with inherited bleeding disorders. Haemophilia nurses are responsible for coordinating all day to day treatment of patients, whether during acute in-patient stays or bleeding episodes, or as part of a long-term educational approach to home therapy (National Service Specification for Haemophilia and related conditions 2006).

As well as the clinical skills in treating this group of patients, the nurses have an organisational role in overseeing the supply of factor concentrates and provide education and advice on disease management. Psychological support, particularly for newly diagnosed families and children with inhibitors, in addition to discussion on the inheritance of haemophilia, is also provided by the haemophilia nurse.

Requirements for adequate nursing cover must be calculated based on the number of patients treated within each haemophilia centre. As a general rule a minimum of x 1 WTE nurse specialist is required per haemophilia centre, with adequate cover provided for study / annual leave etc from an experienced nurse within the haematology service, to ensure continuity of care.

Current nursing provision in Wales

Wales currently has four recognised centres treating patients with inherited bleeding disorders.

1. Cardiff – Comprehensive Care Centre
2. Swansea – Haemophilia Centre
3. Newport – Haemophilia Centre
4. Bangor – Haemophilia Centre

1. Cardiff and SE Wales –

As the only Comprehensive Care Centre (CCC) in Wales, Cardiff offers the full range of specialist services by a complete team of nurses who provide ongoing expertise and knowledge.

Nursing Establishment-

3 x WTE nurses Band 7 x 1 1.6 x Band 6 0.4 x Band 5

1 Band 6 nurse is joint RGN / RSCN and provides a specialist role for children and young people.

Plus 1.4 Research nurses for clinical trials

This establishment provides adequate nursing hours for the Arthur Bloom centre to be self-sufficient in specialist nursing cover during routine working hours. This includes cover for annual leave / sick leave etc.

The nurses deliver all aspects of nursing care through the CCC, providing both inpatient and out-patient care to patients with inherited bleeding disorders. In addition, they provide a role in the community with home visits to patients and families as needed, including school visits.

Paediatrics

The Paediatric specialist nurse is supported by a play therapist 2 days a week primarily to assist with the introduction of home therapy in young children. In addition a paediatrician attends the monthly out-patient clinic and MDT, along with the child psychologist, where current problems / issues can be discussed.

Off-site cover to Llandough for orthopaedic surgery is managed by the haemophilia centre nurses, both during day time hours and at weekends/ evenings as required. This remains the preferred option in order to ensure patients receive the correct treatment in a timely manner when having surgery. Alternative arrangements with hospital at night nurses have been unsuccessful in the past (at Llandough) mainly due to the infrequency of the requirement.

The nursing role is supported by 2.0 WTE admin positions which provide management of the database, blood product ordering and monitoring of stock levels, coordination of the home delivery service and booking all routine appointments for clinical review.

Summary

Current nursing establishment has been developed over the past 10 years and is able to deliver a quality service to patients. The employment of a qualified paediatric nurse from 2003 has been essential in addressing previous gaps in the service provision and ensures all patients receive age appropriate treatment.

It is important to maintain links within haematology and paediatrics in order to provide continuity of service in the future.

2. Swansea and West Wales –

Nursing Establishment - 1 x WTE band 7 clinical nurse specialist RGN

The current establishment in Swansea provides cover for the Haemophilia centre during normal working hours. Annual leave cover is provided by a band 6 haematology nurse with some experience and training in haemophilia care and is able to treat patients with bleeds, issue home treatment etc to cover absences.

Paediatrics

Children access the Paediatric Assessment Unit for out of hours treatment or for treatment of young children with poor venous access, older children are treated by the CNS. For children with inhibitors, care is shared with the CCC in Cardiff. School and home visits are also shared between Cardiff and Swansea nurses.

There is currently no administrative support available for the Haemophilia centre and the CNS delivers all financial reports, coordinates the home delivery service, arranges clinic appointments and submits reports to the National Haemophilia Database.

Summary

At its present level the service is being maintained along with the current level of consultant haematology cover. However, with the current establishment there is little scope for development or ability to increase the number of patients seen e.g. from West Wales. If the service is to develop, administrative support is required to manage financial reports from home delivery of factor concentrates, provide information to

the National Haemophilia Database and to coordinate and monitor clinic appointments and follow up of patients.

3. Newport

Although a registered haemophilia treatment centre, very few patients are seen or treated in Newport. However, in conjunction with the haematology consultant in Newport, development of an outreach service to Nevill Hall hospital would require the establishment of a link nurse for haemophilia patients who could receive training and liaise with the CCC in Cardiff.

4. Bangor

Nursing establishment

Current establishment at Ysbyty Gwynedd is for 1.0 WTE CNS in haemophilia. However, the nurse in post is on maternity leave at this time and worked 0.80 WTE prior to commencement of this leave. Initially no cover was provided for maternity leave although 3 days a week cover has been available for the past few months.

Paediatrics

Support is provided from Alder Hey hospital by the CNS for haemophilia, although distances are an issue and limits the actual amount of input possible. Some assistance is also available from the local community paediatric nurses with venous access in young children with severe haemophilia.

Summary

It is vital that nurse specialist cover is maintained at 1.0 x WTE with provision for cover of all leave in order for adequate delivery of the service to patients. Stronger links to the paediatric nursing service, ideally a part-time paediatric nurse, would strengthen the delivery of an expert service to all patients.

Adequate administrative support is essential to allow patients full equity of access to home delivery of factor concentrates, for general upkeep of the haemophilia databases and monitoring attendances / follow-up appointments etc.

Conclusion

There is currently adequate haemophilia nursing care in SE Wales through Cardiff. The development of haemophilia services in Swansea and Bangor will increase equity of access to expert care for patients. Experienced and qualified specialist haemophilia nurses are essential for the delivery of this care, apart from the major centre (CCC), requires a minimum of 1.0 WTE nurse provision with sufficient cover for all leave. If a successful outreach clinic is to be established at Nevill Hall to extend access to patients in mid and east Wales a 0.5 WTE link nurse would be required. The 1 WTE haemophilia nurse at Bangor should be maintained and a paediatric link established.

The establishment of an Advisory board for Wales, to address the needs of patients with inherited bleeding disorders, would be welcomed and strengthen and develop links across the region. Training needs and education as well as links for support and ongoing review of services would also be a positive outcome of such a group.

Appendix 7 - Provision of Haemophilia Physiotherapy

Identification of gaps in the present service of Physiotherapy management of people with inherited bleeding disorders in South, Mid and North Wales:

Physiotherapy services to this group of patients in Wales is currently provided by 1 WTE position based at University Hospital of Wales, Cardiff. Although the position is full-time, there is no provision for annual leave cover, other than the essential ward-based and Critical care services, where physiotherapy is provided already. 95% of the workload is out-patient based, as it is essentially musculo-skeletal in nature, with involvement of other specialists where necessary, e.g. Neurology rehab.

The role in providing the physiotherapy needs for these patients is essentially divided into 3 areas:

1. Acute interventions

Following bleeds and/or injuries, where the musculo-skeletal system is involved, (bleeds into joints and muscles form the majority, around 85% of the problems) physiotherapy is essential to help to restore the joint or muscle to its pre-bleed status, and to help reduce the long-term consequences of bleeding. Therefore, restoration of Range of Movement, muscle strength length and tone, and restoration of balance proprioception and coordination are essential for aiding recovery and helping to prevent recurrent bleeds due to weakness and inadequate rehabilitation. This treatment needs to be appropriately timed, so that patients do not have to wait on waiting lists for physiotherapy, which could result in further muscle wasting, weakness and recurrent bleeding, not to mention the possible increase in use of blood products due to delay and further bleeding.

2. On-going monitoring / musculoskeletal surveillance

Patients are seen on a regular basis for the physiotherapist to carry out a full and comprehensive Musculo-skeletal review on all severe and moderately affected patients. These assessments follow the H.C.P.A. (Haemophilia Chartered Physiotherapist Association) guidelines, and form part of the recognised level of care to be received by these patients according to National Service Specification for haemophilia and related disorders and the recognised Care Pathway. As a result of carrying out these assessments and discussion with multidisciplinary team, appropriate referrals to orthopaedic clinics can be made.

Due to multiple joint arthropathies and the musculoskeletal nature of the problems experienced by this group of patients, many of them are routinely referred to an Orthotic or Podiatry service in their own area. This is initially for assessment and then provision of specialist insoles or alteration to foot wear.

3. Preparation of patients with inherited bleeding disorders for Orthopaedic surgery

This involves standard pre and post-operative management of the patient, but with the specialist understanding of the complications of operating on such patients. Close liaison with the Therapists managing the patients on-site (usually Llandough), and liaising with other members of the MDT is essential, as factor replacement, pain management and post-operative protocols are complex and differ with each patients.

Close links with Orthopaedic surgeons and their teams involved in the most common areas of joint surgery undertaken in Haemophilia care, i.e. total knee replacements and revision surgery, ankle arthroscopy and arthrodesis and total hip replacement, have been developed.

It is usual in Cardiff for the Physiotherapist to accompany the patient to Orthopaedic clinics where possible, and to help to keep the close liaison between the teams and the patients right through to final rehabilitation and recovery to ensure continuity, optimum care and outcome.

There is currently no dedicated or named Therapist in any of the West, Mid or North Wales hospitals nor in Swansea, to whom patients with inherited bleeding disorders can be safely referred for treatment.

Local services – South and Mid Wales

Patients can, and have been referred to local services on a case by case basis for some time, and in each individual case the patient's particular needs are discussed with an identified Therapist. The bare essentials of haemophilia (or the relevant disorder) are discussed, and although this can work, it has to be repeated for each referral, as it is rarely to the same Therapist.

Patients have been successfully referred to: Carmarthen, Llanelli, Withybush, Pembroke Dock, Aberystwyth, Ammanford, Brecon, Newtown and Nevill Hall. It is a situation which works, but is time-consuming, as it is so important to get the relevant information fully understood in order to ensure the safety and confidence of the patient and Therapist.

A recent example is a patient who came to Cardiff from Swansea for a Specialist Physiotherapy opinion. Had there been a dedicated therapist available this could have been dealt with locally.

North Wales

In North Wales there is no physiotherapy service for these patients, however, a business case is being developed. A recent case illustrates this need as a young man from North Wales with established haemophilic arthropathy of his ankles was sent to Cardiff for an Orthopaedic and Physiotherapy assessment. In such a case, he would benefit from ongoing support and therapy from a therapist with relevant knowledge and experience in his own area.

Sharing of specialist knowledge about bleeding disorders and physiotherapy/ rehabilitation:

The specialist physiotherapist based in Cardiff would be prepared to provide in-Service training to staff, either as general interest to a whole group or specifically to newly appointed or named therapists.

The H.C.P.A. (Haemophilia Chartered Physiotherapist's Association) is a group of approximately 40 physiotherapists who work in this field either in comprehensive care centres and smaller units within the UK. They hold regular meetings and seminars, some of which are held in conjunction with larger multidisciplinary national and international conferences. The group encourage geographical peer support, in smaller groups and on a one-to-one basis. This is necessary, and essential, as the opportunity

to meet is infrequent and relevant in-service training on site is not possible, reflecting the rarity of the conditions treated. Any newly identified physiotherapists would have access to this network,

If there were to be a group of identified physiotherapists involved in each of the various areas in Wales, a Welsh group could be formed to facilitate the learning and provide peer-support.

Recommendations

1. An additional physiotherapist post in Swansea, (based at Singleton Hospital) linked to the Cardiff Comprehensive Care Centre for Continuing Professional Development (CPD), could initially spend time in Cardiff centre and attend the established monthly Outreach clinics, observing and learning about patients with inherited bleeding disorders and the necessary physiotherapy management. Based on the number of patients currently seen in Swansea this would ideally be for 2 days per week (WTE 0.40).
2. Establish an Outreach clinic from the Swansea centre to be held at Withybush Hospital, where the Physiotherapist based in Swansea could see patients from the wider area, reducing the need for them to travel to Cardiff or Swansea for reviews and treatment.
3. To identify a named physiotherapist in DGHs such as Nevill Hall, Carmarthen, Withybush and Aberystwyth to whom referrals could be made and discussed.
4. To meet the increasing physiotherapy workload at Cardiff and Vale UHB for patients with inherited bleeding disorders, an additional post of a static Band 6 WTE should be implemented to improve the service to patients by increasing the available hours of a specialist physiotherapist, as well as provide peer support; holiday and study leave cover and allow for succession planning.
5. To meet the needs of patients in North Wales a 0.4 WTE dedicated specialist haemophilia physiotherapist is required in order to provide the required standard of care for patients.

Appendix 8 - Report and Recommendations to Improve Counselling and Psychological Services Provided to People with Inherited Bleeding Disorders (IBD)

Purpose of the report

This report has been prepared as part of the Medical Director for NHS Wales' task and Finish Group (T&FG) on Haemophilia Services. The report provides a brief summary of current counselling service provision, it analyses the ability to meet existing demand and the ability to meet a projected increase in demand for such services in the future. It proposes recommendations to secure improvements in the availability of such services for inclusion in the Medical Director's Report to Ministers.

Background

On the 8th March 2011 the Minister for Health and Social Services made a statement concerning people infected by Hepatitis C and HIV as a result of infection from contaminated blood products. As a result of a commitment made during her statement a 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. The review was to pay specific attention to the needs, including the counselling needs, of people who have contracted blood borne viruses due to treatment with infected blood products.

The T&FG required that a number of reports were produced to inform the review and produce recommendations for the Minister to ensure service improvements.

In order to prepare this report a visit was made to the Cardiff Comprehensive Care Centre. Relevant literature was analysed, including service user narratives provided to the review on existing service provision and telephone calls were made to staff co-ordinating and delivering haemophilia services in Bangor, North Wales. A brief report provided by the paediatric psychology service at University Hospital Wales has been used in the production of this report and is reproduced at appendix 1. Further information on a stepped care approach based upon NICE Guidance in cancer care and proposals for enhancements to existing services was provided by colleagues in paediatric and medical psychology and has informed the recommended expansion to existing services.

...."Haemophilia is a life long disorder, which affects the whole family. To be effective the social worker needs to fully understand haemophilia and the lifestyle and problems that it brings with it. Added to this the devastating effects of HIV and Hepatitis C and now the added worry of CJD we can think of no other disorder, which requires dedicated social care input."

Mother of a Haemophilia patient South Wales

Defining Counselling Services

Counselling services to people with inherited bleeding disorders can usefully be categorised into three core areas of activity:

Genetic Counselling

The National Service Framework (NSF) for Haemophilia and Other Bleeding Disorders 2006 requires that:

Families should have access to genetic counselling delivered by an individual trained in genetic counselling and knowledgeable about inherited bleeding disorders. Access to genetic counselling may be required before, during and after genetic testing and when considering reproductive choices.

Counselling on Condition Management

The NSF further requires that families and individuals affected with inherited bleeding disorders should have access to information about clinical phenotype, therapeutic options and genetic information relevant to their diagnosis. Specific obstetric, gynaecological and anti natal counselling are also required for women.

Counselling services and clinical psychology

Patients with haemophilia and their family members often have complex psychological issues requiring specialist counselling or clinical psychology input. In addition to counselling needs patients may frequently require social care support.

Some forms of counselling should be delivered on a one to one basis whilst other approaches may be delivered through groups providing peer support or through family interventions most notably where the patient or patients are children.

Patient experiences point to a preference for care to be provided at specialist centres where staff have disease specific knowledge and are skilled in supporting people with long term and life threatening illness. It is important that people who are struggling with current difficulties do not have to face stigma or staff being overwhelmed by the patient's problems.

Psychosocial support should be embedded within the practice of the MDT rather than delivered from an external agency wherever possible and the offer of additional support should be normalised and easy to access.

Practitioners offering additional support from all disciplines need to have experience of a medical setting and their practice needs to be underpinned by models which do not pathologise reactions to illness but support coping and resilience. It is also crucial that this input serves to equip the MDT to deliver psychologically minded approaches.

There is a need for the teams to have dedicated clinical psychology time to provide comprehensive psychological care. The current and future challenges faced by this patient group require the teams to develop a framework for managing anxiety and decision making around treatment and testing.

Experience at the Cardiff centre and from other patient groups suggests a stepped care model is appropriate (e.g. Cancer care, NICE Guidance, 2004). Most psychological care is provided by teams supported by clinical health psychologists who also see a small number of families or individuals who need more specialist interventions. The psychologists provide direct clinical input, joint reviews, consultation and supervision and contribute to service development. The four tiered approach is set out below:

- Level 1** compassionate care - all staff
- Level 2** screening, problem solving – Clinical Nurse Specialists (CNSs), social workers, play workers
- Level 3** interventions for problems such as needle phobia, counselling - CNS's, Social workers, play workers, specialist genetic CNS's
- Level 4** more complex family work, interventions with more significant psychological/mental health problems - clinical health/paediatric psychologists

The psychology posts will deliver training, support and supervision to other staff working at Levels 1, 2 & 3. As clinical health psychologists they can provide valuable indirect input to services, in addition to direct patient care.

The Availability of Counselling and Psycho Social Support for People with Inherited Bleeding Disorders in Wales

In order to address access and reflect variance in the availability of access to counselling and psycho social support for people with inherited bleeding disorders and their families in Wales analysis at a regional level is most useful.

Cardiff Comprehensive Care Centre-South East Wales

Genetic Counselling

This is delivered by the Medical Genetics service in Cardiff. No issues in terms of access were identified.

Counselling on Condition Management

This is delivered by Haemophilia Nursing staff. No issues were raised in relation to provision of this service within the CCC or in liaison with other specialist services.

Counselling services and clinical psychology

The bulk of counselling and PSIs are delivered by the Social Work service delivered within the CCC. This service consists of 1 Whole Time Equivalent (WTE) Social Work post currently provided through a job share. This post was established using resource earmarked for HIV services. The post has therefore predominantly been used to counsel people and to offer social

support to people who have contracted blood borne viruses including HIV and Hepatitis C.

Historically the post had capacity to also provide more general psycho social support to patients and families in coping with IBDs. Ongoing counselling support has been provided to the group of people diagnosed as having contracted a blood borne virus through contaminated blood products. However, the service has more recently been required to deliver counselling and social support to the wider population of people with HIV and Hepatitis C at the University Hospital of Wales. This means that the service is more thinly spread within the CCC and is no longer able to provide counselling and social support to those people within the CCC without a blood borne virus. A post providing PSIs to people with HIV based in Cardiff Royal Infirmary is due to be deleted. This is likely to further stretch the Social Work service available within the CCC. These services are predominantly delivered at the CCC due to limited capacity. Outreach and home visits are not feasible and this has the effect of limiting the reach of the service locally and more importantly to people living at a distance from the CCC. There is no dedicated clinical psychology input for adults within the CCC.

Paediatric Psychology services to the Haemophilia team

In addition to the social work service within the CCC a paediatric Psychology service is provided to the Haemophilia Team. Whilst the service is available it is not currently funded to deliver the service to the team and is therefore somewhat vulnerable. The Clinical Psychologist attends a monthly meeting with the Haemophilia MDT where presenting dilemmas are shared.

Most often families where there have been difficulties coping with the treatment regime, or where children have become phobic or resistant to treatment are discussed. Sometimes the discussion enables staff already working with a family or child to take things forward in a different way, or it may be decided a referral to another agency is needed. At other times it is agreed that the Clinical Psychologist will offer to work directly with a family, either in tandem or in close collaboration with a member of the team. In these cases the meetings also serve (with family's permission) as a forum for feedback and further collaboration. At all times the aim is to think reflectively about both the team and family responses at every level in order to facilitate changes. The amount of direct individual work is limited by current resources.

Particular themes emerge from the work which would inform future service development. The condition affects families over generations hence a life span family orientation on the part of all service providers is helpful.

A regular forum of this kind also provides staff with the opportunity to share concerns and dilemmas in a manner that fosters good team working and mutual support in a challenging work context.

Cardiff Comprehensive Care Centre- South West Wales and South Powys

Genetic Counselling

The arrangements for South West Wales and South Powys reflect those provided to South East Wales. Genetic education and testing are provided in the CCC and at the Haemophilia Centre in Swansea and genetic counselling is provided through the Medical Genetics service in Cardiff. No issues in terms of access were identified.

Counselling on Condition Management

This is delivered by the Clinical Nurse specialist service. No issues were raised in relation to provision of this service within the CCC or in liaison with other specialist services.

Counselling services and clinical psychology

Provision is limited to those services available at the CCC in Cardiff. As is highlighted above outreach is not possible due to limited capacity. This appears gives rise to an inequitable service with those who can more easily attend the CCC receiving a more comprehensive service than those living at a greater distance from the centre.

The paediatric psychology service shall likewise provide services to families through the CCC together with the benefits to the MDT accrued from receipt of advice and a psychological perspective in addressing the needs of families. The paediatric psychology service is not able to offer outreach to the haemophilia centres.

"...As for holistic care then yes, I agree with J's comments about the lack of social care/ counselling available for patients and their families to deal with the stresses of the condition....I have never been offered bereavement counselling for losing my brother to HIV and HepC and I would hope that is something that will be addressed for all those who will have to face up to their loss from here on in.....I received a letter last year wrongly addressed to my son and not me as his parent advising him he was theoretically at risk of vCJD. He opened it. Nobody offered us counselling at the time and just expected us to take it in our stride. It goes to the point I was making about lack of emotional and moral support, certainly in West Wales."

Mother to a young haemophilia patient and sister to a late Haemophilia patient West Wales

North Wales and North Powys

Provision of counselling psychology and PSIs in North Wales and North Powys is less well developed than in South Wales and South Powys. Arrangements are largely ad hoc with aspects of counselling and psychological support at best uncoordinated or at worst absent.

Provision in North Wales is primarily delivered via the Haemophilia centre in Bangor with support from the CCC at Alder Hay Hospital in Liverpool.

Genetic Counselling

Genetic Counselling delivered by Medical Genetics, is well developed with no major issues reported.

Counselling on Condition Management

This has predominantly been provided by a haematology nurse post which was created in 2008. However the post holder is on maternity leave at present and the post has only cover for 6 sessions per week in the interim. As a result this service is extremely limited and the lack of critical mass renders this type of support vulnerable to staffing fluctuations.

Support for some families with children in receipt of prophylaxis is provided at Alder Hay CCC but this requires long journeys for families living in North West Wales. There is some in-reach to the Bangor HC from Alder Hay but this is limited.

Counselling services and clinical psychology

These appear the most underdeveloped of the counselling support services in North Wales and North Powys. No dedicated social work or psychology support is available via the Bangor HC. It is not clear how much support is delivered through mainstream primary care, social care or psychological services through agency referral or self referral. Some but very limited support has been provided by the Health Psychology service which predominantly provides a service to people with cancer. Whilst the service acknowledges the need for people with inherited bleeding disorders and in particular where these are accompanied with blood borne viruses the service is not adequately resourced to meet this need in addition to cancer care. A GUM consultant at Ysbyty Gwynedd is reported to have sought resource from WAG to establish bespoke service provision in North Wales.

"We feel it is inappropriate for Haemophilia patients to be treated with malignant Haematology patients as both needs are very different. There is no counselling available to Haemophilia patients or their families."

Mother of a young haemophilia patient North Wales

"When my son was younger he had 2 portacaths fitted at Alder Hey Hospital, Liverpool. When we were at the hospital we were advised by the Social Worker that we were entitled to the Disability Living Allowance, we received this until C was 10 years old and then it was stopped. There isn't a Social worker at Bangor and we haven't had any advice on what would be available to us. We have never applied for a Disabled Parking Badge and there are no dedicated Haemophilia Parking spaces at the Hospital.....We have never been offered counselling or social work support."

Parent of a haemophilia patient North Wales

"....the families of children with Haemophilia used to get together once every 6mths or so we could help and support each other. This all stopped when Dr T retired, I felt this was very helpful to myself being a new mum and having a

child with Haemophilia, and hearing all other parents experiences and advice really help me to cope with certain episodes and also to bring my child up to the confident young man he is today, shame it hasn't carried on and have lost contact with the parents except one or two."

Parent of a haemophilia patient North Wales

Past Current and Future Service Pressures in Delivering Support to people with Inherited Bleeding Disorders and Blood Borne Viruses

Meeting the psycho social support needs of people with inherited bleeding disorders who have contracted blood bourn viruses through infected blood products has changed since the initial awareness of infection was identified.

Initial work focused upon providing counselling and social support during the period of testing for and confirmation of infection for HIV and Hepatitis C. Those people who have contracted these infections are known. They and their families require ongoing counselling and practical support to manage their condition and to cope with loss and bereavement issues. An exacerbating factor which should not be underestimated is the stigma frequently associated with blood bourn viruses. This stigma can lead to discrimination in the delivery of healthcare and other services. Such discrimination places additional burden on patients and their families requiring significant support and understanding. For these reasons people with blood bourn viruses frequently turn to specialist haemophilia services to meet their needs in the round. As a consequence the specialist service frequently appears to be less well supported by mainstream health and social care support than other tertiary services and is required to "consume its own smoke" in terms of social and psychological support.

The future support needs are likely therefore to include ongoing support for people as they move through various phases of their illness arising from both their bleeding disorder and blood borne viruses. However a significant future pressure is already beginning to bring pressure to bear on these services. People who have received blood products in the past may have contracted new variant CJD. A very small number of cases of new variant CJD have been identified as having been contracted from blood products. However it is by no means clear at this stage to what extent if any this will emerge within the population of people with an inherited bleeding disorder. Nevertheless all people at risk have already received a letter informing them of the potential risk of infection.

The need to avoid potential cross infection from those at risk of new variant CJD is already leading to medical and dental practice which can appear discriminatory and will inevitably raise anxiety for patients and their families.

This in itself has given rise understandably to anxiety which has been expressed. It is anticipated that in the near future a test for new variant CJD will be developed and offered to those at risk. Managing peoples concern pre testing and post testing will create significant demands upon already stretched services or make more apparent the existing services deficits.

Summary of Issues

Services at the Cardiff CCC are the best developed in Wales. Whilst genetic counselling and counselling on condition management appear to be provided to meet identified need, the broader psycho social support especially support for people with blood borne viruses is limited. These services are predominantly provided through Social Work support with limited access to paediatric psychology services. Outreach is limited leading to inequity of provision; the social work service available is stretched due to provision of a wider service to people with HIV and Hepatitis C within the University Hospital Wales. The paediatric psychology service is unfunded. As a result services whilst quite comprehensive within the CCC are vulnerable to resource reductions. They are unable to provide an easily accessible service to West Wales and South Powys and given current limited capacity will be even more stretched to address the anticipated increased need emerging from the work associated with new variant CJD testing.

North Wales' services are far less well developed with gaps in provision within the Bangor HC hub. There is therefore inequity of access within North Wales with only ad hoc arrangements for psycho social support and there is significant inequity of provision between South Wales and North Wales.

A family perspective is very important in delivering care. Links to paediatric services are important. The CCC in Cardiff delivers a service to 185 children, Swansea HC sees 40 children and the Bangor HC approximately 40 children.

Provision of psycho social support to patients with blood bourn viruses and their families is a particular concern. Of the 908 people in Wales with an IBD, 167 (18%) have a blood borne virus, 154 (92%) of these people live in South Wales and South Powys and 13 (8%) live in North Wales and North Powys.

Demand arising from the potential that people may develop vCJD from previous infection needs to be addressed now. Patients at risk of vCJD have been notified support in coping with this is required and in time support for preparation for testing and post testing will be required. Of the 908 people with an IBD, 296 (32%) are identified as being at risk of vCJD. 197 (66%) of these people live in South Wales and 96 (34%) live in North Wales.

Recommendations

- The Social Work Service currently available in the Cardiff CCC needs to be secured and rendered less vulnerable to financial and workforce/workload fluctuations allowing the potential for greater outreach.
- The paediatric psychology service should be secured and strengthened.
- The Comprehensive Care Centre in Cardiff and the Haemophilia Centres at Swansea and Bangor together with the proposed centre in Abergavenny should have dedicated psychology input from a clinical health/paediatric psychologist in the host health

board to facilitate effective team working and liaison with local services. The psychologists should also work as a haemophilia network group to support the teams in both paediatric and adult work, consulting and cross referring according to patient need. The Abergavenny psychologist would work closely with the Cardiff team to provide a service for adults and to help the service meet the anticipated needs of the adult population. The Swansea team will be supported by a department who have a well developed lifespan approach and can provide both paediatric and adult input. The allocation of sessions should be reviewed according to activity in the future.

- Steps should be 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 commissioning of such a service to address the apparent current service gaps.

Costs

The cost of additional psychology sessions is set out below:

Cardiff	0.4 wte 8c	£33,184.40
Swansea	0.2 wte 8c	£16,592.20
Abergavenny	0.2 wte 8c	£16,592.20
Bangor		£30,000

Total £96,368.80

(These figures include on costs but not travel or administration costs)

Appendix 9 - Provision of Hepatology

1) Blood Borne Viral (BBV) treatment and counselling Specialist Nurse input

Currently this service is provided by the haematology team in Cardiff at the CCC but with the development of newer treatments there will be the need for more counselling and treatment services which should be under the supervision of a consultant hepatologist. In other centres, the numbers are low and with the extra input envisaged and funded already by the BBV action plan it will be possible to provide services in Swansea and North Wales without additional specialist nursing and community support worker input.

In the Blood Borne Viral Hepatitis Action Plan for Wales 2010-2015, a nurse led treatment/counselling service is recommended with monitoring case load of 60 patients on treatment or having active monitoring is recommended for each specialist nurse.

Using this level of input as a benchmark and as there are 100 patients currently infected and being managed at CCC in Cardiff, it would work out at 1.6 WTE specialist nurses to provide the service. [This would not be covered by the additional nursing as community support provided to Cardiff as part of the BBV action plan.]

Comment [b1]: Not sure I understand this sentence? Patients with Haemophilia and Hepatitis should already have access to hepatology support as provided by the BBVHAP.

2) BBV treatment and counselling consultant Hepatologist input

For the Cardiff CCC case load, one consultant session of hepatology time a week is also required. This is calculated on the basis again of that in the BBV action plan it specified that 1 session of consultant time per week should be identified to support the additional nurse and community support worker.

This would allow for a clinic at least alternate weeks to be undertaken in the CCC and give a place for joint review of patients with viral hepatitis who are being worked up for and undergoing treatment.

Ideally patients on treatment should be seen by the consultant before starting treatment and at the end and ad hoc through the treatment depending on response to treatment and complications e.g. use of Epo and GCSF. Many of these treated patients will require newer treatments such as telepravir (next to market due Oct 2011) and would need more consultant input than current standard treatment.

The alternate weekly clinic would give sufficient slots (20 clinics per year 6 slots per clinic = 120 slots) for all patients to be seen by the consultant at least once.

For Swansea, there is already dedicated consultant time for hepatology and numbers of patients are small so additional input will not be needed.

In North Wales, there may not be need for more time particularly if bleeding disorder care is centralised on the Bangor site, it would be beneficial if one of the consultants develops a special interest to provide this service. There are currently two FT consultant gastroenterologists and a locum consultant post with a view to a permanent position. Once the third person is in post it would be recommended that each

consultant takes a lead for a sub-speciality within gastroenterology. This reorganisation of workload into hepatology/IBD and endoscopy work-streams should mean that the patients requiring treatment can be managed without additional resource.

3) General Hepatology Services (outpatient)

In the Cardiff CCC there is no outpatient hepatology service. For patients with advanced liver disease or those who have had treatment at a separate clinic alternate weeks would then give another 120 slots per year. If this clinic was co-located in the haematology centre (space allowing) it would be possible to run parallel clinics with the haematologists to minimise patient visits to clinic. This would amount to a further ½ consultant sessions a week and would be available to those who are not suitable for treatment but who need hepatology FU and input and for the monitoring of patients post treatment.

4) General Hepatology Services (inpatient)

Patients admitted with decompensated liver disease should be seen by a specialist within a working day of admission. Almost all teaching hospital (and increasingly DGHs) acute medical services work to this standard with definition of specialist patients to specialist consultants within 12 hours of admission. There are no clear national standards to work to here.

Regardless of where the patients are admitted to (acute medical ward or haematology ward) they should therefore usually be seen within a working day of admission by a hepatology consultant or possibly a hepatology specialist registrar.

Summary Requirements and Recommendations

	CCC-UHW	Swansea	North Wales/Bangor
Hepatology Specialist nurse input	1.6 WTE in addition to the BBV funded posts Suggested 1x band 7 and 0.6 x band 6 in line with BBV action plan	Nil extra required above new BBV action plan provision	Nil extra required above new BBV action plan provision
Consultant Outpatient service	Dedicated 1 session per week	No new input service already supplied by new money from BBV action plan	Reorganisation of current service in Bangor may be required but no new input above BBV action plan
Consultant inpatient service	Current FT consultant vacancy needs to be filled with a specialist hepatologist	As above	As above

Ruth Alcolado Based on recommendations in the BBV Action Plan for Wales

Appendix 10 - Welsh Government Written Response to the Equality of Opportunity Committee's Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers.

Edwina Hart, Minister for Health and Social Services.

June 2010

I welcome this report. Equality and human rights are fundamental values of the NHS in Wales and discrimination against people with HIV is not only unacceptable but is illegal. I am committed to wiping out this type of discrimination wherever it exists in our health service.

Many of the recommendations contained in the report fit well with our current policy direction and I am pleased to be able to accept the majority of them.

One of the key issues that has arisen as part of this Inquiry is the lack of 'formal' evidence available about discriminatory practices. The survey from AIDS Trust Cymru for the Inquiry and more recently the report from the HIV Stigma Index, 'Give Stigma the Index Finger'¹ indicate that some people living with HIV in Wales have experienced different forms of discrimination within the health service. On the other hand, the Inquiry has not uncovered any 'formal' complaints to the NHS on this subject.

I recognise that it is often the stigma associated with HIV that prevents people from speaking out when they have experienced discrimination. I want people with HIV to feel able to report and challenge discriminatory behaviour where it is experienced so that it can be investigated and appropriate action taken.

The findings from the Inquiry suggest that there are different forms of discrimination. It appears that some of the practices that are perceived as discriminatory emerge from a lack of understanding about HIV and the use of universal precautions. It is estimated that one third of people in the UK with HIV are undiagnosed. It is essential that healthcare professionals work within current guidelines to strike a balance between preventing the spread of undiagnosed HIV and other blood borne viruses, and ensuring that patients known to have HIV are not subject to unnecessary additional precautions which would be discriminatory.

I will soon be launching the Sexual Health and Wellbeing Action Plan for Wales. This outlines the Welsh Assembly Government's commitment to continue to improve sexual health in Wales, reduce sexual health inequalities and develop more open discussion about sex, sexuality and sexual health. As part of this Action Plan I have highlighted the need for a renewed focus on HIV prevention and treatment. I am committed to continuing a programme of HIV prevention in Wales, supporting the All Wales HIV Network, and improving the healthcare for people with HIV/AIDS through implementation of

¹ www.ippf.org/NR/rdonlyres/.../0/InitialFindingsStigmaIndex.pdf

‘Providing for the needs of people living with HIV/AIDs in Wales: National Care Pathways and Service Specification for testing, diagnosis, treatment and supportive care’.

As part of the Action Plan work has commenced on reviewing and strengthening the All Wales HIV Network. Management of the Network has been taken over by Public Health Wales with Positive Participation Groups continuing to be led by local HIV charities. HIV network members agreed that the renewed goal for Positive Participation Groups is ‘full and equitable partnership so that policy and practice can be influenced by experience and evidence’. Local Positive Participation Groups meetings have traditionally been attended by local HIV service providers and they provide an ideal forum for feedback to local health boards about the care provided. Part of the role and responsibility of local Positive Participation Groups will be to report back experiences of stigma and discrimination to the wider group. A new website for the All Wales HIV Network is due to be launched at the end of July and an additional confidential internet forum for HIV positive members of the Network is being developed.

The Network is undertaking a needs assessment of people living with HIV in Wales. Part of this assessment will look at experiences of stigma and discrimination. Most people living with HIV are not necessarily in touch with the HIV voluntary sector and it is important that their views are also represented. This assessment will attempt to reach a wide range of people living with HIV. A report is due at the end of July.

Recently the Constitutional Affairs Committee, during its consideration of the Health Protection (Part 2A Orders) (Wales) Regulations 2010, recommended that the Government may wish to consider the impact of these regulations, in relation to issues around stigmatisation of those with HIV or other STIs. The Health Protection (Part 2A Orders) (Wales) Regulations 2010 are made under the amended Public Health (Control of Disease Act) 1984. This Act gives powers to a Justice of the Peace (JP) to make Part 2A Orders imposing restrictions or requirements on people to protect against an infection or contamination that presents or could present significant harm to human health. The regulations supplement the Act by setting out the evidence that must apply before a JP can make an order and providing safeguards to protect anyone who may be subject to an order.

Under the legislation, the JP order making powers are subject to strict criteria and evidential requirements which mean that one cannot be made unless it is necessary to do so and there is no alternative to achieve the desired health protection outcome. The powers are not in place to increase discrimination or stigma experienced by any one particular group.

All orders placing restrictions or requirements on people are restricted to a maximum of 28 days and can be varied or revoked. The regulations require that any orders are reported to Welsh Ministers so that they may be scrutinised and published. This reporting and monitoring of Part 2A orders will

ensure that if there is evidence of orders being used inappropriately against any one group of people, action can be taken.

Whilst it is important to protect the public from the risk of infection or contamination, it is as important to protect individual's rights, and not increase discrimination or stigmatisation experienced by one group of people. The regulations provide effective safeguards to protect people, regardless of their circumstances, against any potential misuse of these powers.

I have set out below my response to the Report's individual recommendations.

Detailed Responses to the report's recommendations are set out below:

Evidence base for Discrimination

1. The Committee welcomes the initiatives introduced by some local health boards to improve the experiences of patients, particularly the patient and public involvement groups set up by Abertawe Bro Morgannwg University LHB and recommends that the Welsh Assembly Government encourage other local health boards to consider implementing similar initiatives

Response: Accept

Involving patients in the development of health services is key to improving the experience of patients in the NHS and I commend the approach taken by Abertawe Bro Morgannwg University Local Health Board.

As mentioned in the introduction to this report, the All Wales HIV Network supports local Positive Participation Groups. Part of the remit of these groups is to provide a platform for service providers and HIV positive people to work together to improve services in their locality. Indeed, in some areas there has been regular attendance from local health service providers at these meetings which have led to improvements in service provision.

I will write to local health boards to ask them to consider what arrangements they have in place to work with HIV positive people to improve their services. I will use this opportunity to highlight the All Wales HIV Network and Positive Participation Groups.

Financial Implications: None. Funding for Positive Participation Groups is within existing budgets.

Complaints

2. The Committee believes that AIDS and HIV charities are in the prime position to advise patients on their legal rights including any rights they have under the Disability Discrimination Act 1995 or future legislation. We recommend that they build upon this role to act as advocates for any patients who wish to pursue legal action as a result of experiencing discrimination and

believe that the Equality and Human Rights Commission should actively use their powers and expertise to support the charities.

Response: Accept

I agree that HIV and AIDS charities have an important role to play in assisting patients who experience discrimination and act as advocates for them where a legal challenge to discrimination is taken forward. However, it is also important that all patients feel able to raise a concern about their healthcare and have it dealt with appropriately and promptly by the NHS organisation concerned, without feeling that they have to have recourse to legal action. I have recently consulted on a set of draft regulations (the draft NHS (Concerns, Complaints and Redress) (Wales) regulations 2010) which will underpin new arrangements for the handling of concerns about the NHS in Wales. These regulations, which I intend to lay before the Assembly after the summer recess, require NHS bodies to make provision for the specific needs of people raising concerns, and to ensure that people have proper information about the process. It is also open to any patient to ask for assistance from the Community Health Council Complaints Advocacy Services should they wish to raise a concern about their healthcare.

Financial Implications: None. This is within the existing remit of the charities and the Equality and Human Rights Commission.

3. We believe that the evidence base for cases of discrimination could be boosted by charities alerting local health boards informally of any instances so that they are aware and can keep a record.

Response: Reject

I agree that we need to boost the evidence base for cases of HIV related discrimination. However, there are a number of potential legal issues which make me unable to accept this recommendation. First, there is concern about the effectiveness of any such records given the informality of the proposed process. Any allegations that were brought to the attention of local health boards in this way would not have been investigated and the account of the complainant would not have been tested. Local health boards could therefore be recording an act of discrimination which, if it had been subject to an investigation, may not have been proven.

Second, complainants may not be happy for their concerns to be passed onto local health boards in this way and may only be prepared to speak to the charities in confidence.

Third, whilst it is proposed that local health boards would only keep an informal record of allegations of discrimination, they would need to consider how they would handle a serious complaint received in this way. If they wished to investigate, this may require the cooperation of the complainant, which the complainant may not wish to do.

Fourth, in the event that local health boards did not need to investigate complaints that were brought to their attention under this process, that could be unfair on the alleged perpetrators of the discrimination. They may never be informed that these complaints had been made against them or given any opportunity to defend themselves and clear their name.

Finally, this type of material could also be covered by the Data Protection Act 1998, which requires various conditions to be met before it can be retained or processed, including a requirement to ensure the information is accurate. The local health boards could therefore be in breach of data protection principles if this information was retained without being verified.

I believe that it is proven cases of discrimination that will build the evidence base. If a patient experiences discrimination they should be encouraged and supported to take forward complaints through the NHS complaints procedure and/or through the relevant professional body for investigation. As I have outlined in my response to recommendation 2, I will be laying down draft regulations to the Assembly that require NHS bodies to make provision for the specific needs of people raising concerns, and to ensure that people have proper information about the process. This includes them being supported through Community Health Council Complaints Advocacy Services as well as HIV charities. Additionally, the All Wales HIV Network's local Positive Participation Groups provide an existing platform for HIV positive people to raise issues with local health boards and to work together to improve services in their locality. I will ask the HIV Network and Community Health Councils to ensure good links are in place between Community Health Councils and Positive Participation Groups.

Financial Implications: None. Any additional funding will be met within existing budgets.

Lack of Information, Experience and Skills

4. The Committee recommends that the Welsh Assembly Government put arrangements in place with local health boards to allow all GP and dental practices to be able to contact a HIV specialist by email or telephone to discuss treatment prior to issuing a prescription. This would ensure that patients receive appropriate medication without having to consult their specialist.

Response: Accept

I agree that a patient's non-HIV related primary care needs should be met by primary care practitioners and not by being referred to their HIV specialist. This will provide a more acceptable service to patients and increase efficiency by reducing unnecessary consultations with HIV Specialists.

Communication between primary care and specialist services is the key to resolving this issue. Where some medication is being provided by a specialist clinic and other routine medications provided through primary care there is a risk that one prescriber may not be aware of changes being made by the other clinician. There is therefore a concern that potential drug interactions might be missed. With detailed and timely communication these issues can be resolved but there are often delays in communication.

There are a number of ways this situation can be improved and electronic communication has a big part to play in resolving these issues. Expert prescribing advice should also be available from local health board pharmacy teams or through consultation with colleagues in specialist clinics as suggested in the recommendation.

Within this context it is also important to acknowledge the role that people with HIV play in challenging poor practice themselves. The Stigma Index Report found that 45 per cent of people surveyed had challenged, confronted or educated someone who had been stigmatising them. In Wales, the Terrence Higgins Trust delivers the Expert Patient Programme specifically for people with HIV. Part of this programme looks at how the patient can work with their healthcare providers. An 'expert patient' may be well placed to challenge what they perceive as inappropriate or unnecessary practice.

I will ask local health boards to consider arrangements that can best support primary care practitioners in the care of HIV positive people

Financial Implications: None. Any costs will be drawn from existing budgets.

Training

5. The Committee recommends that local health boards use the experience of HIV specialist consultants and nurses to provide in-house training on the advancements within HIV care for other medical staff

Response: Accept

In line with the example of good practice provided to the Inquiry by Betsi Cadwaladr Local Health Board, I will ask all local health boards to consider implementing in-house training on HIV care for other medical staff. Additionally, I will ask them to consider how HIV is covered in basic equality training and training associated with the Disability Discrimination Act (2005).

Financial Implications: None. Any additional costs will be drawn from existing training budgets.

Awareness of Cross-contamination Procedures

6. The Committee recommends that the Welsh Assembly Government carry out an exercise to increase the awareness of universal cross-contamination procedures, including displaying information posters in GP surgeries and hospital waiting and consulting rooms.

Response: Accept in principle

A range of information material on universal/standard infection control precautions aimed primarily at NHS staff, produced at local and national level by bodies such as Local Health Boards and the Royal College of Nursing, already exists. In addition, Public Health Wales have developed a number of infection control model policies, including for Occupational Exposure Management (including “sharps” injuries), and the Management of Blood and Bodily Fluids, which are available on the Public Health Wales website. A model policy on transmission-based precaution policies/procedures is in development.

The Welsh Assembly Government and Public Health Wales will explore the possibility of adapting the range of existing materials for use by the public.

Financial Implications: None. Any additional costs will be drawn from existing programme budgets.

Public Awareness

7. The Committee recommends that the Welsh Assembly Government works with the Department for Health to run a nationwide campaign to educate all sectors of society of the facts of HIV in order to erase the memories of outdated campaigns.

Response: Reject

I agree that there needs to be better understanding of the facts associated with HIV. However, I do not believe that there is evidence to suggest that a nationwide campaign would be an effective way of achieving this. HIV/AIDS-related stigma is not a straightforward phenomenon as attitudes towards the epidemic and those affected can vary massively. Reactions to HIV/AIDS will vary between individuals and groups of people. Religion, gender, sexuality, age and levels of HIV/AIDS education can all affect how somebody feels about the disease. A single nationwide campaign is unlikely to address all of these issues.

A multi-faceted approach is required that promotes HIV awareness across different settings, amongst different cultural groups and across ages.

Effective sex and relationships education (SRE) in schools plays an important part in ensuring that young people know the facts about HIV. As part of the forthcoming Sexual Health and Wellbeing Action Plan updated SRE guidance

for schools is being developed. The updated guidance renews the Welsh Assembly Government's commitment for schools to teach about sexually transmitted infections including HIV/AIDS.

It is well established that the stigma associated with HIV can often prevent people from coming forward for testing. The Welsh Assembly Government funds an All Wales HIV Prevention Programme. Part of the work in recent years has included working with African communities where the stigma associated with HIV, particularly for women can be high. Work has been taken forward with community groups and organisations to promote greater understanding of HIV and the benefits of HIV testing. Community based approaches using point of care testing have been developed in Wales to make the testing environment more acceptable.

There is recognition that there needs to be a strengthening of HIV related work in more general sexual health work. Public Health Wales are currently exploring how their local public health teams can be more involved in the delivery of HIV prevention work. The All Wales HIV Network feeds into the All Wales Sexual Health Network. It is envisaged the Sexual Health Network will include a greater focus on HIV. Membership of the Sexual Health Network is wide and it affords opportunities to raise the issue of HIV and discrimination among a wider audience including, education, the youth sector, health visitors, and school nurses.

The All Wales Sexual Health Network will be carrying out a review of sexual health information and resources available in Wales. As part of this review they will consider what is available with regards to HIV/AIDS.

Financial Implications: None. To be taken forward within existing programme budgets.

8. The Committee heard that Body Positive Cheshire and North Wales had already worked with community and voluntary groups to develop their own understanding of HIV. We believe that this is vital to increasing public awareness and that this role should be expanded further. We understand that the charities face difficult financial pressures and would recommend that the Welsh Assembly Government consider introducing specific funding grants for this purpose.

Response: Reject

I commend the work that Body Positive Cheshire and North Wales has taken forward with community and voluntary groups to develop their own understanding about HIV. However, I feel that the opportunity already exists through the All Wales HIV Network's Positive Participation Groups to work more widely with the local community. These groups are led by local HIV charities and in North Wales this role is undertaken by Body Positive. Positive Participation Groups have already worked effectively with local service providers including health and social care and in some areas the police. As

mentioned in the introduction of this paper, the review of the All Wales HIV Network includes the strengthening of these groups.

I will ask the All Wales HIV Network to consider how local Patient Participation Groups can work more closely with community and voluntary groups.

Financial Implications: None. To be taken forward within existing budgets.

Stigma

9. The Committee recommends that the Welsh Assembly Government encourage local health boards to identify options for routinely offering HIV screening, such as through antenatal screening, and roll out a scheme throughout Wales.

Response: Accept in principle

In October 2007 the Chief Medical Officer (CMO) and Chief Nursing Officer (CNO) wrote to all doctors and nurses in Wales about improving the detection and diagnosis of HIV in non-HIV specialties including primary care.² This letter highlights best practice about offering and recommending HIV testing in all healthcare settings. It encourages doctors and nurses to be alert to the circumstances in which it is appropriate to offer and recommend an HIV test.

In 2008, UK National HIV Testing Guidelines³ were published jointly by the British HIV Association, British Association for Sexual Health and HIV and the British Infection Society. These guidelines are intended to facilitate an increase in HIV testing in all healthcare settings as recommended in the CMO letter. Misconceptions remain regarding HIV testing that hinder increased testing. In particular, many clinicians believe that lengthy pre-test counselling is required prior to testing. These guidelines provide the information needed to enable any clinician to perform a HIV test within good clinical practice and encourage 'normalisation' of HIV testing.

As a follow up to their 2007 letter, I will ask the CMO and CNO to write to local health boards drawing attention to the UK National HIV Testing Guidelines and asking what action is being taken to implement these.

Financial Implications: None – any additional costs will be met within existing budgets.

Healthcare Professionals with HIV

² <http://wales.gov.uk/topics/health/ocmo/publications/cmo/2007/hiv/?lang=en>

³ <http://www.bhiva.org/HIVTesting2008.aspx>

10. The Committee recommends that as part of its review the Welsh Assembly Government considers whether the guidance issued by the Department of Health in 2005 could be updated, specifically addressing whether the rule of immediately withdrawing dentists who are HIV positive is proportionate.

Response: Accept

The four UK Chief Dental Officers have endorsed a tripartite working group involving the UK Advisory Panel on AIDS, the Expert Advisory Group on AIDS and the Advisory Group on Hepatitis who are currently carrying out a review of current policy on blood borne virus infected healthcare workers. The review will involve a comprehensive analysis of all relevant evidence and is anticipated to be completed by the end of the year. Any revision of current guidance needs to be based on the best evidence.

Financial Implications: None. This work is being taken forward within existing budgets.

Appendix 11 - Creutzfeldt-Jakob Disease (CJD) Decontamination of medical equipment

During the task and finish group meetings, patient representatives explained that there appears to be confusion within the health service of the procedures to decontaminate medical equipment following a clinical intervention upon a person who has or may be at risk of CJD. Awareness of the procedures that should be followed if a person dies was also queried.

The Advisory Committee on Dangerous Pathogens Transmissible Spongiform Encephalopathy Risk Management Subgroup provides independent scientific advice to the Ministers in the four UK governments. As part of its remit, the group produces the guidance document *Transmissible spongiform encephalopathy agents: safe working and the prevention of infection*. This guidance is available from the Department of Health website at: http://www.dh.gov.uk/ab/ACDP/TSEguidance/DH_098253. The aim of the guidance is the minimisation of the risk of transmission of CJD, and variant CJD (vCJD). All hospitals should be using this guidance.

The current guidance was published in June 2003, replacing the March 1998 edition and continues to be updated as further scientific information becomes available, or future policy decisions need to be reflected. The guidance advises that an assessment be undertaken to find out whether any patient who is about to undergo surgery or endoscopy may be at increased risk of being infected with CJD or vCJD. If a patient is found to have an increased risk, then special infection control precautions may need to be undertaken. Depending on the instrument used and tissue involved in the procedure, this may involve using either a single use instrument or destroying the instrument after use. The advice is clear that the clinical care of patients who have an increased risk of CJD or vCJD should not be compromised in any way.

Guidance on dealing with the bodies of patients with, or at increased risk of, CJD or vCJD, is also contained in *Transmissible spongiform encephalopathy agents: safe working and the prevention of infection* document. This includes advice on carrying out post mortem examinations and transportation of bodies, and advice for undertakers on embalming, funerals and cremations.

Recommendation: Guidance to be reissued to the NHS in Wales and NHS Wales Medical Director to raise the implementation of the guidance with LHB Medical Directors to ensure that all NHS staff are aware of the procedures that should be followed.

Prion decontamination soak

A specific question was asked by patient representatives regarding the use of a new product to decontaminate medical equipment. The question was: *Professor John Collinge, Medical Research Council Director, Prion Unit has developed a Prion Deactivation Soak which is not currently being used in any UK hospital.* The question why this technology is not being used, was asked.

Professor Collinge has a commercial interest through his directorship and shareholding of D-Gen Limited (London) an academic spin-out company which licensed the use of its technology to the DuPont Corporation for the manufacture of the prion decontamination product, Rely+On. This product has been developed to remove prion proteins from surgical instruments.

Rely+On has twice been submitted to the Department of Health's Rapid Review Panel (RRP). The RRP is responsible for providing an assessment of new and novel equipment, materials, and other products or protocols that may be of value to the NHS in improving hospital infection control and reducing hospital acquired infections. On the first occasion in June 2007 Rely+On was recommended as being a potentially useful product but insufficiently validated and therefore more research and development was required before it would be ready for evaluation in practice. There were also several issues concerning the product, in particular that the suggested use of Rely+On which involved soaking instruments in open troughs containing the agent, is unacceptable and the product exhibited excessive frothing, making it unusable in washer/disinfectors. The product had also not been assessed against an animal model which most closely replicates the situation with vCJD in humans. Rely+On was re-submitted to the RRP in December 2008 and awarded a Recommendation 2 (product has potential). However, it was still being recommended for use in open troughs and had not been assessed against the recommended prion (BSE mouse) model. The RRP provided detailed feedback to DuPont.

In April 2010, DuPont accepted an offer from the RRP to work with an Infection Control Product Specialist who convened an expert group to work with Dupont. The group established the gaps within the company's RRP application, together with advice on how it could be improved. This was sent to DuPont in September 2010. To date, the RRP have not received a further application from DuPont, and it is now understood that DuPont have decided to not continue with the development of this product. Other potential prion removal products have been through similar RRP processes, with similar results, and therefore have not yet proven suitable for use in the standard decontamination cycle in healthcare.

The Department of Health has recently announced that it will be making available £2.4 million over the next 4 years to commission a programme of decontaminated-related research. This will support, amongst other things, the development of cold plasma decontamination technologies, specifically for use on instruments such as endoscopes and research to optimise the effectiveness of automated washer disinfectors used to wash and sterilise surgical instruments.

Appendix 12 - Other Issues

Data Management

Accurate recording of clinical information is essential for the effective delivery of haemophilia care. Both the North Wales and the Mid and South Wales plans recognise the need to improve data management. Record keeping and data collection should comply with the requirements set out in the Haemophilia Alliance National Service Specification for Haemophilia and Other Bleeding Disorders, 2006.

Recommendation

LHBs must provide appropriate resources to ensure information is submitted to the national haemophilia data system, thereby enabling real time capture of information, including patient registration details and coagulation factor usage

Services for Children and Young People/Play Therapists

The All Wales Universal Standards for Children and Young People Specialised Healthcare Services state that specialised healthcare services must be adequately staffed with appropriate, multi-disciplinary professionals who are fully trained and equipped to deliver care services across the network. This includes an action that play specialists should be employed in all appropriate areas of the service.

The National Service Framework for Children, Young People and Maternity Services in Wales places children, young people and their families at the centre of service delivery by ensuring that services are designed to meet their particular needs. Standards have been set for children and young people who suffer acute and chronic illness and injury. All children, young people and parents/carers should receive support and information to enable them to understand their condition, treatment and care and are encouraged to be active partners in decisions that affect them. Their care is well co-ordinated across the various providers and systems, with a clear point of contact for the key elements of support. They receive timely, high quality, and where possible, evidence based care delivered by appropriately trained staff in an environment which is safe and well suited to their age and stage of development. The transfer from children's services to adult services is planned with the young person and their parent/carers to ensure smooth transition.

The Bevan Foundation Report on Fair Play for Disabled Children in Wales (2010) notes that:

the line between play and therapy is not clear. Some activities that are classified as therapies are seen as activities or play by the children. Therapists play a key role in play and encourage children's development through a wide range of activities and can encourage parents to play more with their children.

Physiotherapists are key providers of information about activities for disabled children and young people.

Recommendation

LHBs must ensure that services for children and young people with bleeding disorders meet the requirements 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

Dentistry Services

Severe haemophiliacs are treated in District Hospitals/District General Hospitals as a speciality in restorative dentistry. Less severe patients have their own Factor 8 and are treated in the primary care sector and generally considered competent in the self-management of their condition. There are general capacity issues about the ability to access appointments in the secondary sector for all groups of patients not just haemophiliacs.

Recommendations

A clinical care pathway should be developed for patients with inherited bleeding disorders

A Specialist in Special Care Dentistry to be responsible for all medically compromised patients

Access to Treatment Centres

Concerns were raised with the Group about the Welsh Ambulance Service taking patients to the most appropriate rather than the local hospital and when accessing services outside of the haemophilia centre patients often encounter problems particularly when accessing care out of hours.

Haemophilia centres already issue patients with a “Green Card” to alert other health professionals about their condition and where to obtain specialist advice. They contain the patient’s demographics, GP information and the centre at which they are registered together with the diagnosis, with relevant factor levels and a space for free text, where preferred treatment or additional information is required. There are problems with these as patients often forget to carry their cards or they may be ignored by medical staff who do not understand its significance.

In the haemophilia centre in Cardiff, they have an additional mechanism of inserting stickers into the front cover of the current volume of notes, for patients with haemophilia, detailing their diagnosis, presence of inhibitors and current treatment. This is reviewed annually, or when there is a significant change in practice.

The NHS in Wales is taking a number of steps to improve access to patient information. Staff working in hospitals have traditionally relied on a combination of computer systems and paper records to record information about patients and their care with separate systems dealing with different information such as:

- test results
- discharge letters
- referrals

administration details

To address this the NHS in Wales have developed the Welsh Clinical Portal, which is a secure healthspace uniting key patient information from the many computer systems and databases used in NHS Wales, such as those found in pathology, radiology, cancer and primary care settings. The portal provides fast access to information about medication, referrals and discharges, allows health professionals to request tests and results from various sources and ultimately improves patient safety and a reliance on paper records.

In addition, electronic individual health records have been developed which contain a summary of important information from a patients GP medical record, including:

- name, address and contact details
- current medication
- allergies or any adverse reactions
- current problems or diagnosis

The record can be accessed by the Out of Hours GP service and staff within an emergency unit.

Recommendation

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.