

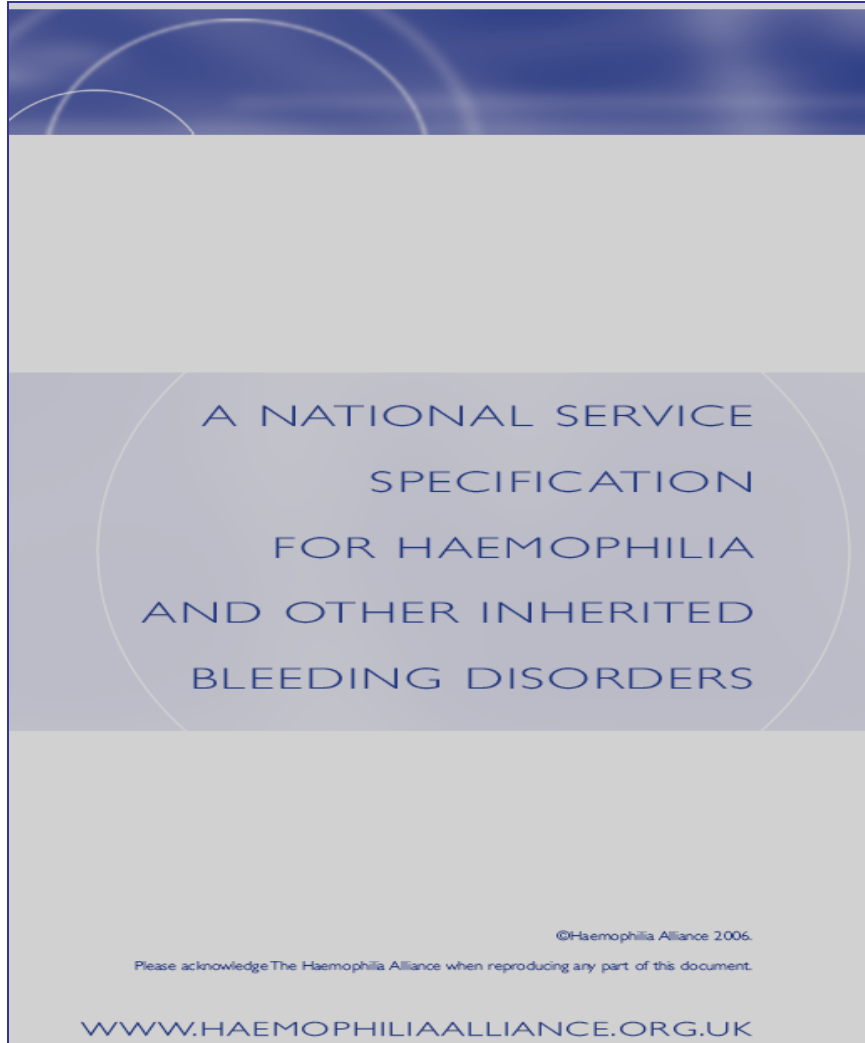
Progress and Lessons Learned

Audit of Hemophilia Treatment Centres in the U.K. and Ireland

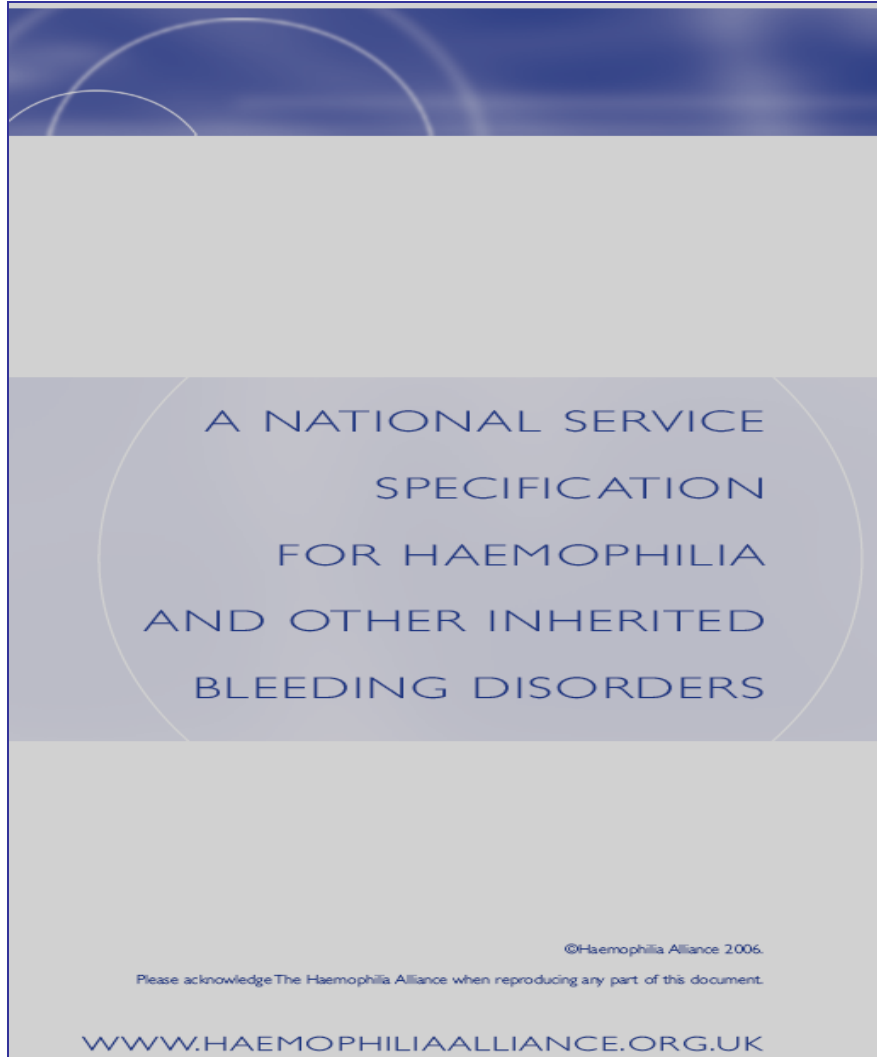
David Page
National Executive Director
Canadian Hemophilia Society
Toronto, November 14, 2009

- Formed in 1999
- Includes:
 - Haemophilia Centre Doctors Organisation (UKHCDO)
 - The Haemophilia Society (patient organization)
 - RCN Haemophilia Nurses Association
 - Haemophilia Chartered Physiotherapists Association
 - Haemophilia Social Workers Group
 - Clinical Scientists Group for Haemophilia
 - Institute of Biomedical Sciences

National Service Specification

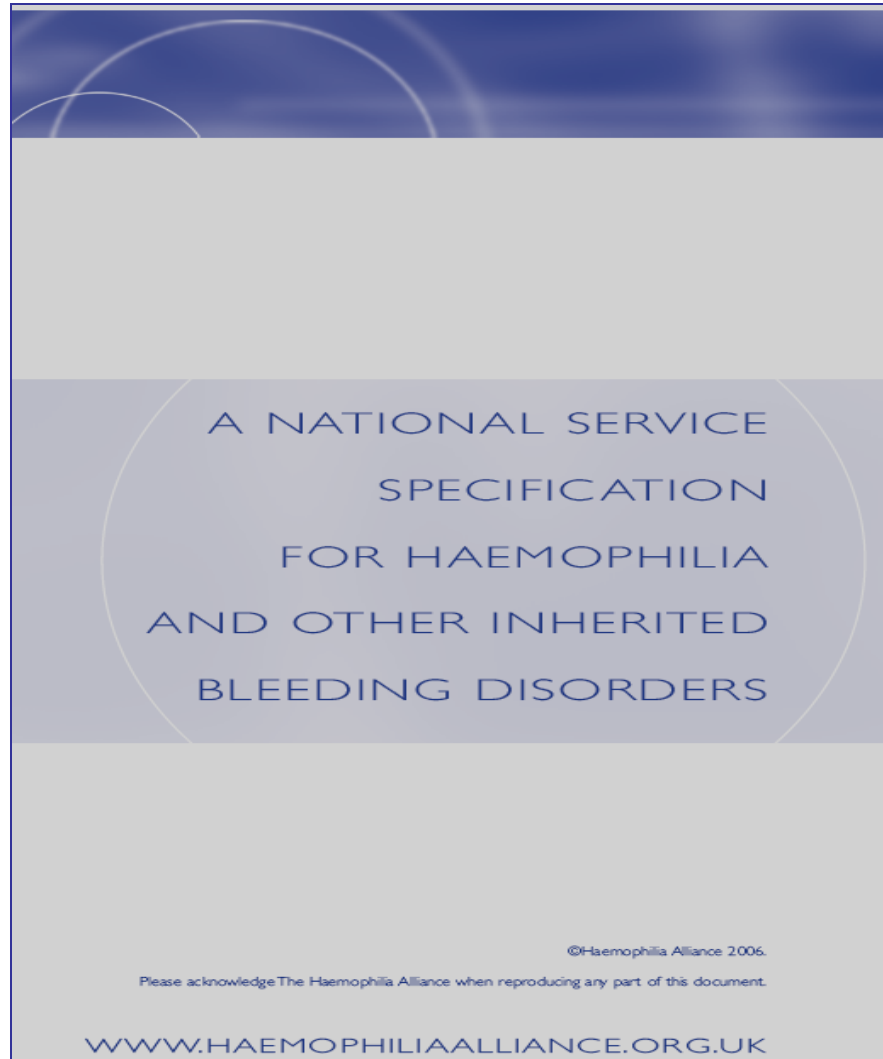


- Produced a National Service Specification (2001)
- Revised 2006
- Reviewed every 3 years
- Basis for audit of UK HTC's
- See www.haemophiliaalliance.org.uk



Aims

- To inform those responsible for commissioning haemophilia services of the recommended standards of care that should be available for all patients with inherited bleeding disorders
- To standardise high quality haemophilia treatment across the UK



Use

- Informs audit tool for external peer review of CCCs
- By commissioners – often as basis for their own documents
- By haemophilia professionals making cases for maintenance/development of service

Audit of the Irish Hemophilia Treatment Centres



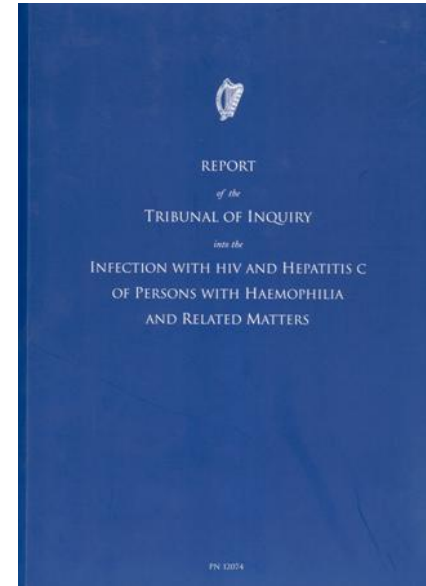
- Canada
 - 9.98 million km²
 - 33 million people



- Ireland
 - 0.08 million km²
 - 4.2 million people



- Statutory body, established in 2004 following Inquiry
- Advises Minister on all aspects of care and treatment for haemophilia
- Ministry, Paying Authority, Clinicians, Haemophilia Society



Organisation of Care

- 3 Comprehensive Care Centres
 - Dublin
 - Adult
 - Paediatric
 - Cork
 - Adult and Paediatric



2006: First Audit

- 2006: First audits carried out – UKHCDO template used. Paid for by hospitals with approval by NHC.
- Deficiencies in staffing in Dublin (paediatric) and Cork
- Infrastructure deficiencies in Cork
- Requirement for in-patient designated beds in Dublin (adult)



- No patient representative
- UK system allows for patient representative but rarely used
- Irish Haemophilia Society adamant that patient representative be included on future audit teams
- IHS Proposal Accepted
- Patient representative from abroad selected by CEO and Board of Irish Haemophilia Society



Scope of Patient Representative

- Audit of physical facilities
- Audit of services
- Discussion on patient needs
- Review of anonymous patient questionnaires
- Discussion on human resources
 - Policies and procedures
 - Discussion with individual staff
- Confidentiality training



Scope of Medical, Nursing Auditors

- Additionally included: Examination of individual patient records



- NHC met senior health service staff and Minister
- Outlined deficiencies identified in 2006 audit not yet corrected
- Warned that poor audit report inevitable unless resources made available



- 2006 audit reports on website and made available to the media
- Media coverage of deficiencies in service
- Mainstream media and medical press

Cork haemophilia centre 'inadequate'

IRISH TIMES 15/09/08

EITHNE DONNELLAN,
Health Correspondent

THERE ARE major deficiencies at the centre which provides care to people with haemophilia in Cork, according to external auditors.

The auditors, who visited the facility at Cork University Hospital in 2006 and are due to return again at the end of this month, found the infrastructure at the unit "very poor and grossly inadequate".

They found no dedicated space for the care of patients with haemophilia. "At times patients have to be moved from one space to another in the middle of a consultation or procedures cancelled at

short notice due to lack of a place," their report said.

It added: "The facilities significantly hamper the delivery of effective and efficient care for patients with inherited bleeding disorders."

The UK auditors recommended that dedicated space be found for the haemophilia centre and that a consultant be employed to take overall responsibility for the unit.

The auditors also inspected the paediatric haemophilia centre at Our Lady's Hospital for Sick Children in Crumlin, Dublin, and the national centre for adults at Dublin's St James's Hospital. At Crumlin they identified the need

for a clinician to lead the haemophilia service and at St James's the need for protected beds for inpatients with haemophilia.

The audits were ordered by the National Haemophilia Council, which was established following the recommendations of the Lindsay Tribunal, which inquired into the infection of haemophiliacs with HIV and hepatitis C by contaminated blood products.

Its chairman Prof John Bonnar said yesterday the recommendations of the auditors had been passed to the HSE and the hospitals, and he expected them to be delivered on within the next year.

A centralised inpatient unit with protected beds at St James's

has now passed the design stage. But the infrastructural problems in Cork have still to be addressed.

Brian O'Mahony, chief executive of the Irish Haemophilia Society, said, however, that the HSE was now examining a proposal for a modular centre in Cork.

He pointed out that the activity on these recommendations had only taken place in recent months, as a fresh audit was about to begin to check what had been acted on.

Meanwhile, a European haemophilia conference at Dublin Castle at the weekend heard how new technology has the potential to allow women carriers of haemophilia to have children without the condition by pre-selecting the

embryos to be implanted in their womb. A small number of children without haemophilia have already been born in this way, using pre-implantation genetic diagnosis.

It also heard how techniques are now being developed to allow a carrier of haemophilia, in the first two months of pregnancy, to ascertain whether her foetus is male and has the condition. Prof Flora Peyvandi, an Italian haematologist, said this would allow mothers to prepare for the birth or to seek a termination.

Prof Bonnar said that a child born in the Republic now with haemophilia will have a normal life expectancy. "This is an amazing advance," he said.



The state of haemophilia services

With an audit scheduled for later this month, Lloyd Mudiwa finds that moves to improve haemophilia services may be coming too late to impact the review

The Chief Executive of St James's Hospital, Dublin, promised auditors, during the last audit of the haemophilia service in the Hospital in November 2006, that an inpatient facility will be in place within two and a half years.

A patient asked to comment about the service at the Hospital in the same audit – a part of the peer-reviewed triennial audits of the three main comprehensive haemophilia care centres in Ireland – commented: "I am very grateful to the service we receive from all the carers, who are our friends as well as medical providers."

The promise and the patient's comment best sum up the state of haemophilia services in Ireland: Blessed with a hard-working and professional staff, but lacking in sufficient facilities and other resources including staff.

Apart from St James's Hospital, Our Lady's Hospital for Sick Children, Crumlin, Dublin, and Cork University Hospital (CUH)

"We have had constructive meetings with the Department of Health and the National Hospitals Office, and a lot of progress has been made in moving forward. I think there is a degree of understanding.

"One of the main advantages of having a Council in place, which we have pointed out to the Department of Health and the HSE, is that we set out clearly what we feel are the priorities for all the comprehensive centres.

"This gives them a very clear mandate, not just of clinicians, but also of the IHS, HSE and the Department of Health.

"The Department and the HSE have to recognise that rather than having 20 or so hospitals submitting their requirements, it is beneficial to have the Council shortlist the absolute priorities for three main centres, particularly given the recession. But then, you do expect to get movement if you are going to get competent services"

Mr O'Mahony explained that

of a formalised 24-hour on-call rota for specialised coagulation tests.

Although patients were admitted to the haematology/oncology ward, it is often difficult to find a bed and the ideal would be a new dedicated inpatient facility for haemophilia.

However, St James's Hospital will finally be going to tender shortly for the construction of a centralised inpatient unit for haemophilia and hepatology in the Hospital (*IMN 01/09/2008*), said Mr O'Mahony, who hoped it would be completed in 2009/2010.

The auditors also mentioned that as a national centre for specialised coagulation tests, the NCHCD should offer von Willebrand factor (vWF) multimers, platelet nucleotide and Factor VIII (FVIII) binding in-house, rather than sending these to the UK.

When patients were asked to comment on what was particularly good about the centre, the most common response was the staff.



St James's Hospital, Dublin

with bleeding episodes. Consequently, the outpatient reviews are carried out by another doctor who comes from St

James's Hospital, the audit report stresses.

However, Mr O'Mahony highlighted that a modular centre

es and storage of medical reports of patients with inherited bleeding disorders, which should be readily available on a 24-hour

2008 – Pre-audit activity

- Funding made available for additional consultant posts
 - Dublin, Cork
- Funds for Centre for Cork
- Funds for Secretary for Cork
- In-patient unit previously confirmed (by Minister at IHS Annual Conference)



2008 - Audits

- Team of 3
 - Physician, UK
 - Nurse, UK
 - Patient representative, Canada
- Audit of 3 centres
 - 1-day audit in each



2008: Second Audit

- Prior publicity and meetings ensured participation of hospital CEOs
- Centre staff very aware of importance

“An indispensable element in assisting us to optimise our service to persons with bleeding disorders and their families”



2008 Audit - Report

- Dublin (adult)
 - Centralised and protected beds for in-patients
 - Role as a National Centre expanded
- Dublin (Paediatric)
 - New Consultant.... **Appointed**
 - Additional Clinical Nurse specialist.... **funding approved**
 - Laboratory should offer 24/7 vWD assays
 - Role as a National centre required clarification



2008 Audit Reports

- Cork
 - Dedicated Centre... **Funding made available**
 - Haemophilia secretary ... **appointed**
 - New lead Consultant... **appointed**



External Peer Audits

- Crucial element in identification of deficiencies and improving care
- External Quality Assurance System accepted for laboratories
- Examine service through the prism of others' experience



External Peer Audits

- Health service and Ministry attach more importance to external audits
- More interesting for media
- An imminent audit focuses the staff and budget holders on correcting previously identified deficiencies



External Peer Audits

- Incomplete without patient representative
- Brings different perspective and experience to team
- Increases confidence of the patient organization in the process
- Advantages of audits obvious to Health care workers, Haemophilia Society, National Haemophilia Council and Ministry of Health



- Audits viewed as positive and helpful
- Seen as assisting them in identification of deficiencies in service and in obtaining resources required
- Degree of apprehension before first audit; not seen with subsequent audits
- More preparatory work required for first audit

“Inclusion of a patient representative was great as he asked different and very relevant questions.”

“ I feel that the process gave me recognition for the work that I do.”

“ Will help me to improve how I do my job.”



Acknowledgements

- Brian O'Mahony, CEO, Irish Haemophilia Society
- UK Haemophilia Alliance
- Irish National Haemophilia Council

