

WITN3289007

CURRICULUM VITAE
CHARLES RICHARD MORRIS HAY

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QUALIFICATIONS:

MB ChB	1976 (Sheff).	MD	1990
MRCP	1980.	FRCP	1994
MRCPath	1984.	FRCPPath	1996

PRESENT POST:

**Clinical Professor of Haemostasis and
Thrombosis.**
Consultant Haematologist.
**Director, Manchester Haemophilia
Comprehensive Care Centre.**

DATE APPOINTED:

1/12/94

PREVIOUS POSTS (IN REVERSE-CHRONOLOGICAL ORDER):-

May 1987-November 1994. Senior Lecturer in Haematology, University of Liverpool.
Honorary Consultant Haematologist. Director Mersey Region Haemophilia Centre.
Royal Liverpool University Hospital Trust. Prescott St. Liverpool, L7 3BX.

Aug. 1982-May 1987 Rotating Senior Registrar in Haematology, Hon. Clinical Tutor.
Sheffield University Hospitals. Prof FE Preston, DR DA Winfield, Dr JS Lillyman.

Aug 1979-AUG 1982 Junior Registrar in Haematology, Northern General Hospital (T),
Sheffield. Dr ACK Lawrence, DR MJ Brown.

Aug 1978- Aug 1979 Junior Medical Registrar, St Mary's Hospital London W9. Dr R
Elkeles, Dr H Tunstall-Pedoe.

Aug 1977-Aug 1978 Senior House Physician, Royal Hospital, Sheffield. Dr J J Daly,
Dr D Cullen.

March 1977-Aug 1977 House Physician, Haematology and General Medicine,
Sheffield Royal Infirmary. Prof EK Blackburn, Dr FE Preston, Dr D Holdsworth, Dr JD
Ward.

Aug 1976-March 1977, House Surgeon, University Dept of Surgery, Royal Infirmary,
Sheffield. Prof HL Duthie

PROFESSIONAL AFFILIATIONS AND LOCAL NATIONAL AND INTERNATIONAL COMMITTEES:

PROFESSIONAL AFFILIATIONS AND LOCAL, NATIONAL AND INTERNATIONAL COMMITTEES:

Local Committees:

Chairman, North West Non-Malignant Haematology Speciality Group of the **NIHR (CRN) since 2011.**

Regional Haematologists Committee.

National Committees:

Haemophilia CRG member 2013-16.

Clinical Lead; DH National Procurement Team, UK Coagulation Factor Procurement 2005/6 and 2009/10 (seconded part time to DOH 1/9/09-1/9/10).

Member of the Advisory Group, and reporting to, the Health Protection Agency and DH Blood Policy Unit on vCJD since 2009-11. (still reporting to them quarterly through the Database).

Northern Representative. **Haemophilia Clinical Reference Group** advising the **National Commissioning Board** and then **NHS England** since 2011.

North West Research Lead for Non-Malignant Haematology Speciality Group of the **NIHR (CRN)** since 2011.

Member of the Advisory Group to the Dept of Health on support for individuals infected with hepatitis C or HIV by blood transfusion or blood products since 2008 (still meets occasionally).

Secretary Haemophilia Alliance 1999-2005.

Fellow and external examiner of the Royal College of Pathologists since 1993.

UK Haemophilia Centre Directors Organisation (UKHCDO):

Chairman UK Haemophilia Centre Doctors Organisation (**UKHCDO**) 2005-2011.

Director, of the **UK National Haemophilia Database (NHD)** since 2002.

Vice-Chairman UKHCDO 1997-2005.

Treasurer of the UK Haemophilia Centre Directors Organisation (UKHCDO) 1992-97.
Trustee of UKHCDO 1992-to date.
Managing Director **UKHCDO Ltd** since 2003.
Chairman: UKHCDO Inhibitor Working Party 1993-2005.
Chairman, UKHCDO Data Management Group 1998-2005 (member since)..
Member of the Committee of Regional Haemophilia Centre Directors of the UK 1987
Member Therapeutic Guidelines Taskforce of UKHCDO 1996.
Member Information Technology Working Party of UKHCDO 1996-98.
Member of the UKHCDO Paediatric Working Party 1993-2005.
Member of the UKHCDO Von Willebrand Working Party 1996-2000..

International Committees:

Member of the Scientific Committee of the World Federation of Haemophilia since 1993-96
International Advisory Committee of the International Society on Thrombosis and Haemostasis.
Steering Committee member European Haemophilia Adverse Event System (EUHAS).
Co-Chair of Factor VIII and IX Scientific Standardisation Subcommittee of the ISTH 2007-11.
Member of the advisory group to the Journal of Thrombosis and Haemostasis, The Journal of ISTH 2007-11.
Chief Investigator International Immune Tolerance Study Group 1999-2014.
Member of the International Immune Tolerance Study Group since 1996.
Founder Member of the Editorial Board of "Haemophilia" the Journal of the World Federation of Haemophilia (Wiley-Blackwell) since 1993.

Professional Affiliations:

Fellow of the Royal College of Physicians (1994).
Fellow of the Royal College of Pathologists (1996)
Member British Society of Thrombosis and Haemostasis since 1986.
Member British Society of Haematologists since 1987.

Member International Society of Thrombosis and Haemostasis (ISTH) since 1987.
Member of The American Society of Haematology 2000.
Co-Chair ISTH Factor VIII and IX Scientific Standardisation Sub-Committee 2007-11.

I review regularly for the following journals: -

The British Journal of Haematology.
The Journal of Thrombosis and Haemostasis,
Blood, the Journal of the American Society of Haematology.
Haemophilia, the Journal of the World Federation of Haemophilia.
The British Journal of Anaesthesia,

UKHCDO and National Haemophilia Database:

The **UK Haemophilia Centre Doctors Organisation (UKHCDO)** was set up with the **National Haemophilia Database (NHD)** when Haemophilia Centres were formed in 1968. It has a membership of about 150 Haemophilia Centre Doctors and seconded specialists and officers of the organisation are elected. The organisation formulates treatment and healthcare policy, conducts clinical research, formulates national published guidelines and monitors disease for DH and HPA. These guidelines are very well respected and even copied internationally.

As vice Chairman and Chairman over a period of 12 years, I was forged much closer links with DH and Commissioners to create and consolidate a central administrative and healthcare planning role for UKHCDO. We now enjoy a collaborative working relationship with NHS England, the Health Protection Agency and The Central Medicines Unit. Fruits of this collaboration include, Recombinant Factor VIII/IX for all, four rounds of National Commissioning, which reduced the price of factor concentrates by two thirds saving at least £75 million/year

The National Haemophilia Database (**NHD**) was established in Oxford in 1968 as a disease register, registering all diagnoses of bleeding disorders in the UK and also basic treatment data and treatment complications and adverse events. In 2002, the

database was transferred to Manchester under my directorship. Since that time, and with the support from two full time statisticians and a team of software engineers, we have increased the scope and capacity of the database enormously and established the enterprise on a solid financial footing. All Haemophilia Centres and all patients on home therapy are now networked to the database. The database holds records on about 25,000 patients with bleeding disorders, with detailed bleed-level treatment data, data on complications, HIV, HCV and vCJD. We produce an annual statistical report (written by me) and also quarterly reports of various types for HPA (vCJD monitoring), contract monitoring (for DH and CMU), post-marketing pharmacovigilance studies for Industry and regulators and disease/treatment monitoring for Specialist Commissioners. The database has also become a powerful research tool and is now recognised to be the most powerful and sophisticated Bleeding Disorder Database in the world.

NHD is funded by DH grants NHS England, NHS Wales and NHS Scotland and Industry. NHD is administered by UKHCDO Ltd, of which I am Managing Director, and the UKHCDO Data Management Working Party.

Department of Health:

I have been a regular advisor to the Department of Health in various areas connected with haemophilia care for more than a decade. The main areas in which I have provided advice data, support and leadership are hepatitis C, HIV and vCJD, haemophilia care in general and National Procurement of Clotting Factor Concentrates. These include: -

Advice on the setup of the **Skipton Fund** for remuneration of patients infected with HCV in 2003;

Advisory panel on revision of awards from the Skipton Fund 2010 and 2012 (Chaired by Prof Brian Gazzard);

Leading and directing the **National HCV Lookback Exercise** on behalf of DH 2010-13 (using the National Haemophilia Database (NHD)).

Oral (X2) and written (6 reports) evidence to the **Penrose Inquiry** into HCV and HIV in

patients with bleeding disorders 2009-13.

Advising and reporting to DH and Health Protection Agency on vCJD in patients with bleeding disorders 2004-date (collated and reported on all the original reports of potential exposure and quarterly reports from NHD for the past three years.)

Advisory Panel on Recombinant Factor VIII for All 2004-6. (I also modelled and supervised this process 2005-7, using the National Haemophilia Database).

National Clinical Lead 1st National (UK Excl. Scotland) Procurement Scheme for clotting factor concentrates 2006/7 (in partnership with Deloitte and Central Medicines Unit (CMU) (*saved £50M/year*).

National Clinical Lead 2nd National (UK Wide) Procurement Scheme 2009/10 (Seconded part-time (2 days/week) to DH for 12 mths) in partnership with CMU.

National Clinical lead 2009/10 National Contract for home delivery of clotting factor concentrates.

Regular meetings with DH Blood Policy Unit every 6 mths or so 2004-2011 to discuss issues in relation to haemophilia care.

Research Contributions:

1.) Publications:-

I have published >180 original articles **My h-index is 32 (i.e. I have published 32 papers cited at least 32 times) and is rising.**

Organisation and promotion and/or management of research:-

I have built up a research group in the **National Haemophilia Database (NHD)** supported by two WT statistician to be used as a resource for myself and the UKHCDO Working Parties to produce treatment statistics for healthcare planning and disease (e.g. haemophilia HCV, HIV and vCJD) monitoring. The NHD Group has become an internationally recognised and respected research group investigating the epidemiology, natural history and treatment of bleeding disorders. This has led to a large number of original reports in recent years (9 authored or co-authored by me in the last decade) with a number of others in preparation. My main

area of research activity within this group concerns the epidemiology and risk-factors for factor VIII inhibitors.

NHD also hosts and partners EUHASS (below) the EU-funded, Europe-wide Bleeding Disorder adverse event network as Co-applicant and Partner of an EU grant for approximately 3 million Euros over 3 years 2009-12. Manchester was awarded 40% of the total. The main applicant was the University of Sheffield Dept. of Haematology. A further EU grant for 1.5 M Euros for 2012-15 follows on.

We also have a small clinical trials group, which conducted the recently concluded, investigator-led Randomised **International Immune Tolerance Study** (ITI study) in 69 centres in 17 countries of which I was **Principal Investigator** with Prof DM Dimichele from Cornell, overseeing the management of the ITI study and associated studies to investigate induction of tolerance. This ground-breaking trial has recently been described in Blood (Hay and DiMichele, 2012) but will yield a further 8 to 10 publications over the next two years. The study cost \$7.5M to run over almost ten years. We also participate in a number of other phase-1 to phase 4 clinical trials. I am chief investigator for a number of these and am Regional Chair of the Non-Malignant Haematology CLRN.

Co-Chair International Society of Thrombosis and Haemostasis factor VIII and IX SSC 2007-11. This committee is a focus not only for standardisation but investigator-led multinational research. The group promoted the ITI study and an ongoing system to explore the risk factors for factor VIII inhibitors (see above).

The group as a whole have also yielded three recent PHDs (Steve Keeney, Megan Sutherland and Jill Pike).

Clinical:

I am director of the Regional Thrombosis and Haemostasis Centre serving the North West of England. This provides a supra-regional diagnostic and clinical Thrombosis and Haemostasis Service supported by nationally recognised Thrombosis and Haemostasis Laboratories.

Teaching, Speaking and Scientific Meetings:

I am frequently invited to give plenary lectures at symposia at scientific meetings, including the main International meetings such as The International Society of Thrombosis and Haemostasis (ISTH), The International Society of Haematology (ISH), the European Society of Haemophilia and Allied Disorders EAHAD and the American Society of Haematology (ASH) but also local national meetings. I teach undergraduates and postgraduates on a regular basis and am co-organiser of a long-running and popular national coagulation course that runs for 6 days every six months. We host SSC students on average twice yearly.

We are a World Federation of Haemophilia Training Site and host doctors from the developing world for training attachments lasting 6-8 weeks about every six months.