

UKHCDO Advisory Committee

Chair	Dr Ri Liesner	Great Ormond Street Hospital, London
Vice Chair	Prof Peter Collins	Cardiff
Secretary	Dr Kate Talks	Newcastle
Treasurer	Dr Pratima Chowdary	Royal Free Hospital, London

A representative from each CCC

Dr Sarah Mangles	Basingstoke
Dr Gary Benson/Dr Christine Macartney	Belfast
Dr Charles Percy/Dr Will Lester	Birmingham Adults
Dr Jayashree Motwani	Birmingham Children's
Dr Oliver Tunstall	Bristol
Dr Emily Symington/Dr Will Thomas	Cambridge
Dr Rachel Rayment	Cardiff
Dr Ryan Rodgers	Edinburgh
Prof Campbell Tait/Dr Elizabeth Chalmers	Glasgow
Dr Ri Liesner	Great Ormond Street Hospital, London
Dr Gillian Evans	Kent & Canterbury
Dr Michael Richards/Dr Lishel Horn	Leeds
Dr Richard Gooding	Leicester
Prof Cheng Hock Toh	Liverpool
Prof Charles Hay	Manchester Adults
Dr John Grainger	Manchester Children's
Dr John Hanley/Dr Kate Talks	Newcastle
Dr Charlotte Grimley	Nottingham
Dr Nicola Curry	Oxford
Prof Amit Nathwani / Dr Pratima Chowdary	Royal Free, London
Prof John Pasi	The Royal London Hospital
Dr Rashid Kazmi	Southampton
Dr Gerry Dolan	St Thomas', London
Prof Mike Makris/Dr Jeanette Payne	Sheffield

Working party Chairs not included above

Dr Rhona MacLean	Co-Morbidities Working Party
Dr Keith Gomez	Genetics Working Party
Dr Dan Hart	Inhibitor Working Party
Dr Tina Biss	Prophylaxis Task Force
Prof Mike Laffan	VWD Working Party

Additional members

Dr Tim Nokes	Representing Haemophilia Centres
Dr Julia Anderson	Representative for BSHT
Drs. Beatrice Nolan/Niamh O'Connell/ James O'Donnell	Honorary representatives from Dublin

Working Parties

Working party rules

1. When a new Working Party is formed all UKHCDO members will be informed of the terms of reference and invited to nominate themselves or others to Chair or serve on the Working Party.
2. The Chair and executive of UKHCDO will appoint the Working Party Chair from those who have applied to join. Working Party Chairs should not have retired from clinical practice. An individual can only be the chair one Working Party at any one time. The Chair and executive of UKHCDO and the Working Party Chair will agree the Working Party membership jointly and this may include individuals who are not members of UKHCDO.
3. Working Parties may be for a fixed term or roll over continuously. The Advisory Committee will decide this.
4. Fixed term Working Parties are set up for a period of three years, after that they will either be given a one-year extension by the Advisory Committee, lie fallow or be re-formed for a further three years. If a one-year extension is granted then after that time they must either lie fallow or be re-formed for a further three years.
5. For Working Parties that roll over, the Chair of UKHCDO will repeat the invitation for applications to join the Working Party every three years. The Working Party Chair may be reappointed for a second term but an individual can only serve two terms as chair (total of 6 years).
6. The new or reappointed Chair and the Chair and executive of UKHCDO will review the membership including new and repeat applications. There is no limit to the duration of individual Working Party membership but, depending on the number of applications, it is expected that one third of the Working Party will change every three years. The Advisory Group should approve the new membership of the Working Party.

Data Management Working Party (continuous)

Chair & Vice Chair of UKHCDO

Prof Peter Collins

Membership

Will Horsley

Prof Charles Hay

Emma Franklin

David Stephenson

Liz Carroll

Dr Gerry Dolan

Dr Rob Hollingsworth

Barry Flynn

Prof Peter Collins

Dr Elizabeth Chalmers

Dr Gary Benson

Commissioner Representative

Director (s) of the National Haemophilia Database

Haemophilia Nurses Association Representative

Haemophilia Physiotherapists Group Representative

Haemophilia Society Representative

Haemtrack User Group Chair

MDSAS Representative

Patient representative

Representative of Wales

Representative of Scotland

Representative of N. Ireland

UKHCDO Working Party Chairs

Dr Rhona MacLean

Dr Keith Gomez

Dr Dan Hart

Dr Will Lester/Vince Jenkins

Dr Pratima Chowdary

Dr Liz Chalmers

Dr John Hanley

Prof Mike Laffan

Co-Morbidities Working Party

Genetics Working Party

Inhibitor Working Party

Laboratory Working Party

Musculoskeletal Working Party/UKHCDO Treasurer

Paediatric Working Party

Peer Review Working Party

Von Willebrand Working Party

UKHCDO Executive Committee (that are not listed above)

Dr Ri Liesner

Dr Kate Talks

UKHCDO Chair

UKHCDO Secretary

Members of the NHD Nominated by the Director(s) of the National Haemophilia Database

Lynne Dewhurst

Bruce Cowen

Ben Palmer

Dr Hua Xiang

Data Managers Forum / Working Party Secretary

UKHCDO Working Party Chair to send another Working Party Member as a representative if the Working Party Chair is unable to attend.

Data Analysis Group (Est. March 2017)

Co-Chairman	Prof Peter Collins	University Hospital Wales
Co-Chairman	Prof Charles Hay	Manchester Royal Infirmary
Secretary	Lynne Dewhurst	National Haemophilia Database

Membership

Dr Elizabeth Chalmers	Glasgow Children's Hospital
Dr Pratima Chowdary	Royal Free Hospital, London
Bruce Cowen	National Haemophilia Database
Simon Fletcher	Churchill Hospital, Oxford
Dr Dan Hart	The Royal London Hospital
Dr Ri Liesner	Great Ormond Street Hospital, London
Ben Palmer	National Haemophilia Database
Paul Sartain	Patient Representative
Dr Martin Scott	Manchester Royal Infirmary
David Stephenson	Kent & Canterbury
Dr Hua Xiang	National Haemophilia Database

Haemtrack Working Group (Est. April 2013)

Chairman	Dr Gerry Dolan	St Thomas' Hospital, London
Secretary	Lynne Dewhurst	National Haemophilia Database

Membership

Nancy Brodie	Glasgow Royal Infirmary
Dr Pratima Chowdary	Royal Free Hospital, London
Bruce Cowen	National Haemophilia Database
Prof Charles Hay	Manchester Royal Infirmary
Dr Dan Hart	The Royal London Hospital
Dr Rob Hollingsworth	MDSAS
Dr Lishel Horn	St James' University Hospital, Leeds
Dr Ri Liesner	Great Ormond Street Hospital, London
Ben Palmer	National Haemophilia Database
Prof John Pasi	The Royal London Hospital
Debra Pollard	Royal Free Hospital, London
Dr Martin Scott	Manchester Royal Infirmary
Antony Woolcomb	Bristol Haematology & Oncology Centre
Dr Hua Xiang	National Haemophilia Database
Patient Representative	(position currently vacant)

Genetics Working Party (Until April 2018)

Chair	Dr Keith Gomez	Royal Free Hospital, London
Secretary	Prof John Pasi	The Royal London Hospital

Membership

Dr Nicola Curry	Churchill Hospital, Oxford
Dr Gerry Dolan	St Thomas' Hospital, London
Dr Steve Keeney	Manchester Royal Infirmary
Prof Michael Laffan	Hammersmith Hospital
Megan Sutherland	Manchester Royal Infirmary

Laboratory Working Party (Est. January 2018)

Co-Chair	Dr Will Lester	Birmingham Queen Elizabeth
Co-Chair	Vince Jenkins	Cardiff
Secretary	TBC	

Membership

Dr Steve Austin	St Georges Hospital, London
Annette Bowyer	Sheffield
Clive Burgess	Great Ormond Street Hospital, London
Dr Pratima Chowdary	Royal Free Hospital, London
Una Jarrold	Edinburgh
Paul Murphy	Royal Victoria Infirmary, Newcastle
Sean Platton	The Royal London Hospital
Anne Riddell	Royal Free Hospital, London
Dr Elaine Gray	NIBSC UK
Dr Steve Kitchen	Sheffield

Inhibitor Working Party (Est. July 2017)

Chairman
Secretary

Dr Dan Hart
Dr Kate Talks

The Royal London Hospital
Royal Victoria Infirmary, Newcastle

Membership

Dr Elizabeth Chalmers
Prof Peter Collins
Dr Georgina Hall
Prof Charles Hay
Dr Ri Liesner
Prof Mike Makris
Ben Palmer
Dr Charles Percy
Anne Riddell

Glasgow Children's Hospital
University Hospital Wales
Churchill Hospital, Oxford
Manchester Royal Infirmary
Great Ormond Street Hospital, London
Sheffield Royal Hallamshire
National Haemophilia Database
Birmingham Queen Elizabeth
Royal Free Hospital, London

Co-Morbidities Working Party (Est. January 2018)

Chairman
Secretary

Dr Rhona MacLean
TBC

Sheffield Royal Hallamshire

Membership

Dr Gary Benson
Dr Jason Coppell
Dr Gerry Dolan
Dr Gillian Evans
Dr Bella Madan
Prof Mike Makris
Dr Sarah Mangles
Dr Susie Shapiro
Cathy Harrison
Fionnuala Sayers

Belfast
Exeter
St Thomas' Hospital, London
Kent & Canterbury
St Thomas' Hospital, London
Sheffield Royal Hallamshire
North Hampshire Hospital, Basingstoke
Oxford
Sheffield
Belfast

Musculoskeletal Working Party (Est. January 2017)

Chairman Dr Pratima Chowdary Royal Free Hospital, London
Secretary TBC

Membership

Mr Peter Briggs	Royal Victoria Infirmary, Newcastle
Mr Stephen Classey	St Thomas' Hospital, London
Dr Desmond Creagh	Royal Cornwall Hospital
Dr Gerry Dolan	St Thomas' Hospital, London
Prof Simon Frostick	Royal Liverpool University Hospital
Mr Nicholas Goddard	Royal Free Hospital, London
Dr John Hanley	Royal Victoria Infirmary, Newcastle
Dr Angela McKernan	Royal Derby Hospital
Paul McLaughlin	Royal Free Hospital, London
Angela Westoby	St James' University Hospital, Leeds
Anna Wells	North Hampshire Hospital, Basingstoke

Paediatric Working Party (Est. June 2017)

Chairman Dr Elizabeth Chalmers Glasgow Children's Hospital
Secretary Dr Jeanette Payne Sheffield Children's Hospital

Membership

Dr Jayanthi Alamelu	Guys & St Thomas Hospital, London
Dr Neha Bhatnagar	Churchill Hospital, Oxford
Dr Tina Biss	Royal Victoria Infirmary, Newcastle
Dr Mary Mathias	Great Ormond Street Hospital, London
Dr Jayashree Motwani	Birmingham Children's Hospital
Dr Mike Richards	St James' University Hospital, Leeds
Dr Oliver Tunstall	Bristol Haematology & Oncology Centre

Peer Review Working Party (Est. December 2016)

Chairman	Dr John Hanley	Royal Victoria Infirmary, Newcastle
Secretary	Dr Julia Anderson	Edinburgh

Membership

Dr Tina Biss	Royal Victoria Infirmary, Newcastle
Dr Elizabeth Chalmers	Glasgow Children's Hospital
Dr Gillian Evans	Kent & Canterbury
Dr Lishel Horn	St James' University Hospital, Leeds
Dr Ri Liesner	Great Ormond Street Hospital, London
Dr Rhona MacLean	Sheffield Royal Hallamshire
Dr Tim Nokes	Plymouth
Dr Kate Khair	Great Ormond Street Hospital, London
Cathy Harrison	Sheffield Children's Hospital
Anna Wells	North Hampshire Hospital, Basingstoke
Helen Aiston	North Hampshire Hospital, Basingstoke
Sarah Bowman	Sheffield Royal Hallamshire
Liz Carroll	Haemophilia Society Representative
Dr Anne Yardumian	North Middlesex

In Addition

Graham Knight	Patient Representative
Rachael Blackburn	WMQRS
Sarah Broomhead	WMQRS
Tim Cooper	WMQRS

Von Willebrand Disease Working Party (Est. August 2017)

Chairman	Prof Mike Laffan	Hammersmith Hospital
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Membership

Dr Anne Goodeve	Sheffield Children's Hospital
Dr Keith Gomez	Royal Free Hospital, London
Vince Jenkins	Cardiff
Dr Will Lester	Birmingham Queen Elizabeth
Dr Carolyn Millar	Hammersmith Hospital
Dr Susie Shapiro	Churchill Hospital, Oxford
Dr Henry Watson	Aberdeen
Dr Thynn Thynn Yee	Royal Free Hospital, London

In Addition

Prof Charles Hay	Manchester Royal Infirmary
Lynne Dewhurst	National Haemophilia Database
Dr Rob Hollingsworth	MDSAS

Task Forces

Task Force rules

1. Task Forces are set up to complete a clearly defined piece of work such as writing a guideline. The task should usually be completed within a year.
2. The UKHCDO Chairman will appoint the Task Force Chair who will agree proposed membership with him.
3. The Advisory Group needs to approve the terms of reference and the membership of the Task Force.
4. No Task Force should contain more than two Consultants from the same institution.
5. Task Forces must report on their progress to each Advisory Group meeting.
6. Task Force Chairs are responsible for ensuring the procedure for UKHCDO guidelines is followed or for obtaining permission from the advisory board not to follow the procedure.

Gynaecology Task Force (Est. January 2018)

Chair	Dr Nicola Curry	Churchill Hospital, Oxford
Secretary	TBC	

Membership

Dr Rezan Abdul Kadir	Royal Free Hospital, London
Dr Louise Bowles	The Royal London Hospital
Dr Gillian Lowe	Birmingham Queen Elizabeth
Dr Jason Mainwaring	Bournemouth/Poole
Dr Sarah Mangles	North Hampshire Hospital, Basingstoke
Dr Bethan Myers	Lincoln
Dr Justin Clark	Birmingham Queen Elizabeth

Prophylaxis Task Force (Est. May 2017)

Co-Chair	Dr Tina Biss	Royal Victoria Infirmary, Newcastle
Co-Chair	Dr Rachel Rayment	University Hospital Wales
Secretary	TBC	

Membership

Dr Steve Austin	St Georges Hospital, London
Dr Elizabeth Chalmers	Glasgow Children's Hospital
Dr Richard Gooding	Leicester Royal Infirmary
Dr Anne Kelly	Addenbrookes Hospital, Cambridge
Dr Susie Shapiro	Churchill Hospital, Oxford
Dr Kate Talks	Royal Victoria Infirmary, Newcastle
Dr Oliver Tunstall	Bristol Haematology & Oncology Centre

Other Committees

None at present