

Clinical Outcomes Group

Membership

John Pasi	Chair
Chris James / Georgie Robinson	Haemophilia Society
Nicola Howe	Pan Thames Haemophilia Consortium
Sue Mather	North West Specialised Commissioning Team
Emma Franklin	Haemophilia Nurses
Rob Hollingsworth / Ben Palmer	National Haemophilia Database
Gerry Dolan	
Charles Hay	
Andrew Will	
Savita Rangarajan	
David Allen	Patient representative
David Stephenson / Paul McLaughlin	Physiotherapists

Remit

To agree and develop a core set of clinical outcome measures that can be applied universally across UK haemophilia / IBD practice and used in a prospective manner

To define such outcome measures to enable simple and reliable employment

Background and activity since September 2011

The Clinical Outcomes Group has not met formally since the last AGM.

The Clinical Outcomes Group was formed as sub-group of the Data Management Working Party in order to facilitate the development of the agreed set of clinical outcomes. A set of agreed outcomes as measures was presented at the last AGM in 2011 and has been discussed at Advisory Boards subsequently.

The proposed measures included:

- Treatment recording and collection of bleed level data nationally using HAEMTRACK
- A definition set for bleeds and prophylaxis
- Joint scores using HJHS and a modified HJHS
- Patient reported activity lists as a surrogate QoL indicator
- Agreed patient contract

This year has seen discussions regarding the implementation of this package and the logistic requirements, which for some centres had been identified as clear challenges on a number of levels.

A proportion of the planned implementation work has been overtaken by the development of the national dashboard, which took some of these outcomes measures over. More recently the Clinical Reference Group within the national commissioning structure has also taken some of these measures and developed them into CQUIN targets for 2013-14.

The proposed outcome measures will, therefore, be incentivised to be delivered through the CQUIN framework.

From the Clinical Outcomes Group, some work remains regarding finalising and fine tuning the paperwork and data collection / data sets for these measures to ensure that there is a standard nationally, but it is envisaged that the Clinical Outcomes Group will shortly complete these. These will provide a 'toolkit' for centres to use and help support centres in providing the outcomes measures required and meet the CQUINs.

Prof KJ Pasi
Chairman, Clinical Outcomes Group
September 2012