

European Haemophilia Consortium Round Table of Stakeholders

Haemophilia registries and clinical outcomes

Tuesday 18 February 2020, 10.00-12.00 hrs

European Parliament – room PHS 1C47

Brussels, Belgium

DRAFT AGENDA

09.00 – 10.00	Registrations
10.00 – 10.05	Welcome and introduction <i>Katalin Cseh, MEP</i>
10.05 – 10.20	The use of registries for regulatory purposes: the vision of the EMA <i>Caroline Voltz (video conference)</i>
10.20 – 10.50	Challenges with data collection for clinical and regulatory practice in haemophilia care <i>Results from the EDQM consensus meeting: Marie-Laure Hecquet, EDQM</i> <i>Issues with European and global approaches to data collection: Cedric Hermans, Cliniques Universitaires St Luc</i>
10.50 – 11.00	Q&A and Discussions
11.00 – 11.15	<i>Why do we need data collection for clinical practice and what can be gained from it – A case study from Ireland</i> <i>Niamh O’Connell, St James’ Hospital</i>
11.15 – 11.30	Clinical and patient-reported outcomes in novel technologies- Where are they now and where they should go? <i>Declan Noone, EHC President</i>
11.30 – 11.50	Q&A and Discussions
11.50 – 12.00	Conclusions <i>Katalin Cseh, MEP</i>

