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**JANSSEN SIGNS FIRST TWO DATA CENTRES TO ITS  
HAEMATOLOGY OUTCOMES NETWORK IN EUROPE (HONEUR)**

Improving results for patients  
by realising the transformational potential of Real World Data

**BEERSE, BELGIUM, 11 April 2019** - The Janssen Pharmaceutical Companies of Johnson & Johnson have announced today the first two data centres to join the HONEUR collaborative network.

HONEUR (Haematology Outcomes Network in Europe) is a Janssen-led initiative and part of the company's overall commitment to creating better outcomes for patients – in this case, by harnessing the full potential of Real World Data and the insights it can provide.

Through a secure, collaborative platform, HONEUR enables participants across Europe to accelerate research and improve conclusions by analysing treatment data from as many sources as possible. The ultimate goal is that patients with blood cancer would receive the best possible treatment due to health data research being widely shared and smartly managed.

The first site to join the HONEUR network is the **UK's Leicester Royal Infirmary**. Dr. Mamta Garg, Consultant Haematologist, MD, FRCP, FRCPath (Haematology), said, "My colleagues and I at the Leicester Royal Infirmary are passionate about the development and use of database records in haematological disorders, as they provide a source of invaluable information for benchmarking, education and research purposes. Joining HONEUR brings us a big step closer to generating Real World Evidence that ultimately has a meaningful impact on patients."

Also joining the HONEUR initiative is The **Registry of Monoclonal Gammopathies (RMG)** in the Czech Republic. Established in 2007, the RMG is funded by the Czech Myeloma Group (CMG) and has become one of their flagship projects. "We are delighted to be one of the first sites to become an HONEUR member," said Prof. MUDr. Roman Hájek, CSc. "Our registry currently includes four haematological malignancies (multiple myeloma; monoclonal gammopathies of undetermined significance; AL amyloidosis; and Waldenström's macroglobulinemia) and we are very much looking forward to collaborating with Janssen and other HONEUR members, so that we can make significant inroads in treating patients with these rare blood diseases."

Martin Price, VP, Health Economics, Market Access & Reimbursement (HEMAR) at Janssen, said, "There's a critical need to increase the impact of Real World Data, so we can advance our understanding of long term outcomes and develop better treatment options for blood cancer patients. These first two signings mark an important milestone in establishing a large-scale, federated network of data centres to help realise this aspiration. It's great to have Leicester Royal Infirmary and RMG on board."

### **Why HONEUR?**

HONEUR was created to help address the challenges of Europe's health data collection landscape, where a group of systems that are often duplicative, uncoordinated and use different languages mean the potential of Real World Data is significantly under-utilised.

Randomised clinical trials often provide only limited answers to research questions. For example, in rare blood diseases such as multiple myeloma, there is a lack of detailed, objective knowledge on routine clinical practice (e.g. selection and duration of treatment), treatment patterns and outcomes in different patient subgroups at different stages of the disease.

In structuring the collaborative HONEUR network, the top priorities were making sure that participating sites maintain local governance at all times and allowing all participants to initiate their own research questions.

One of the keys to tapping into the potential of Real World Data is ensuring the clinical and biological vocabulary, as well as the structure of the data, are as homogeneous as possible. This requires a common data model, because the data sets found across Europe are understandably diverse. The model chosen for HONEUR is OMOP (Observational Medical Outcomes Partnership), developed by the [OHDSI](#) collaboration.

### **Patient Privacy**

The entire HONEUR platform is designed with patient privacy at its core. All local data are pseudonymised and stay local; in most cases only aggregated results are exchanged within the central HONEUR portal. In all circumstances the applicable data protection rules and regulations are complied with and appropriate privacy safeguards are put in place. The transfer of the results happens over a secure connection and, on the portal itself, results are encrypted and only accessible to the researchers who participated in the study.

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### **About the Janssen Pharmaceutical Companies of Johnson & Johnson**

At the Janssen Pharmaceutical Companies of Johnson & Johnson, we are working to create a world without disease. Transforming lives by finding new and better ways to prevent, intercept, treat and cure disease inspires us. We bring together the best minds and pursue the most promising science. We are Janssen. We collaborate with the world for the health of everyone in it. Learn more at [www.janssen.com/emea](http://www.janssen.com/emea). Follow us at <http://www.twitter.com/janssenEMEA>. Janssen-Cilag International N.V. and Cilag GmbH International are part of the Janssen Pharmaceutical Companies of Johnson & Johnson.