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Janssen Signs Six More Data Partners To Its Haematology Outcomes Network In Europe (HONEUR)

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

BEERSE, BELGIUM, 17 December 2019 - The Janssen Pharmaceutical Companies of Johnson & Johnson announced today that six more data partners have joined the HONEUR collaborative network.

The newly joined partners are:

- The Research Institute Hospital 12 de Octubre (i+12) in Madrid
- The Kazakh Institute of Oncology and Radiology in Kazakhstan
- The University of Perugia's Department of Medicine in Italy
- The Czech CLL Study Group in the Czech Republic
- The Medical University of Innsbruck in Austria
- A group of hospitals from the Aragon region in Spain

With these partners joining the UK's Leicester Royal Infirmary and The Registry of Monoclonal Gammopathies (RMG) in the Czech Republic, the HONEUR network now comprises 49 data partners with information on more than 13,000 patients.

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

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 receive

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the right treatment at the right time, through health data research being more widely shared and more smartly managed.

Dr. Augustin Gómez de la Cámara, Head of Clinical and Epidemiological Research at i+12, said, "Building on our tradition of high-quality standards and excellence in research, 12 de Octubre University Hospital is committed to collaborating in initiatives that offer the best chances for success. We're very confident that becoming a member of the HONEUR network will enable us to maximise the value of our Multiple Myeloma data so that we can ultimately improve healthcare for our patients."

Prof. Dilyara Kaidarova, Director of The Kazakh Institute of Oncology and Radiology, said, "In this digital era, it is very important to leverage technology to obtain meaningful insights from the data. We are very impressed with the capabilities provided by the HONEUR platform. We are looking forward to collaborating with Janssen and other HONEUR network partners to unleash the transformational potential of real-world data."

Martin Price, VP, Health Economics, Market Access & Reimbursement EMEA at Janssen Pharmaceutica NV, said, "HONEUR already serves as a robust foundation from which members can initiate research questions, and the more we expand, the more effective the network becomes. We're delighted to welcome these six new data partners 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 underutilised.

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 partners maintain local governance at all times and enabling all participants to initiate their own research questions.

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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 Janssen, we're creating a future where disease is a thing of the past. We're the Pharmaceutical Companies of Johnson & Johnson, working tirelessly to make that future a reality for patients everywhere by fighting sickness with science, improving access with ingenuity, and healing hopelessness with heart. We focus on areas of medicine where we can make the biggest difference: Cardiovascular & Metabolism, Immunology, Infectious Diseases & Vaccines, Neuroscience, Oncology, and Pulmonary Hypertension.

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