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Press Release: Real World Evidence data, key to equitable health care systems?

Brussels, 7 March 2017 – People with Multiple Sclerosis (MS) living in the European Union could receive timelier access to safer and more efficient therapies and could become important partners in the regulation and pricing of medicines.

The key to turning these possible scenarios into reality is the better exploitation of so-called Real World Evidence (RWE) data.

This was the main conclusion of a European Parliament debate co-organised by the European Multiple Sclerosis Platform (EMSP) and MEP Cristian Buşoi (EPP) on 7 March.

The organisers proposed a pressing question to the multi-stakeholder attendance: **“Can Real World Data Advance the Equity of Health Care?”**

“We need better data for better patient-related health outcomes”, MEP Buşoi said.

“Real world evidence data already supports patient advocates but also regulators, payers and researchers to find answers for many key questions. As an example: RWE can give an indication on whether work-focused MS therapies are cost-effective and ultimately bring a societal contribution.”

What is RWE data?

It is a category of disease-specific data being collected outside of the pre-defined area of clinical trials. It can come from clinical practice, prescription data bases, patient registries, social media or pharmacovigilance - the monitoring process carried out on drugs that have obtained marketing authorisation in the EU.

Patient registries

EMSP provided a relevant example of how RWE data can be collected and managed.

*“Within our **EUREMS** project 13 national MS registries showed that the temporary pooling and analysis of patient-driven MS data on European level does function”,* EMSP External Affairs Director Christoph Thalheim explained.

“Commonly agreed «minimum data sets» can be applied as standard for all MS registries as part of a European Network of national MS registries. But for this to happen we need political will and a reasonable level of funding via public/private partnerships.”

EMSP’s plan is to promote this Network as “one-stop provider for MS patient data” in areas where national data collection does not provide sufficient depth.

Better quality of life with early treatment and diagnosis

Neurologist and MS researcher Gavin Giovannoni presented convincing arguments from the **MS Brain Health** project on the importance of early diagnosis in MS. This could lead to more efficient treatment and higher quality of life for patients.

Health economist Gisela Kobelt provided proof along the same lines as Prof. Giovannoni with her presentation on the new **Cost of Illness** study - completed by 17,000 MS patients from 16 European countries. Dr. Kobelt called for health care costs to be assessed as investments from a societal point of view.

Neurologist Maura Pugliatti further substantiated these points with her presentation on the **Value of Treatment (VoT)** project, a multi-stakeholder initiative led by the European Brain Council (EBC). VoT proposes a model of integrated care for brain disorders - such as MS - that can close the treatment gap in Europe.

The way forward: multi-stakeholders collaboration

The debate also allowed representatives of patient organisations, regulators, health care providers and health care technology assessment (HTA) bodies to discuss how RWE data can become the co-driver of regulatory decisions.

A commonly accepted scenario was that both regulators and payers should make recommendations to the patient registries on core data and quality parameters so that the resulting data collections can support decisions on pricing and reimbursement of medicines.

What is MS?

Multiple Sclerosis is one of the most common long-term conditions affecting the central nervous system (brain and spinal cord) and the main cause of non-traumatic disability in young adults. MS is a neurodegenerative disease, a group of conditions that includes Parkinson's and Alzheimer's. It affects more than 700,000 people in Europe. To date it has no cure.

Who is EMSP?

An umbrella organisation for 40 patient organisations across Europe. It is firmly committed to its ultimate vision of a world without multiple sclerosis. EMSP works to ensure that people with MS have a real voice in determining their own objectives and priorities. Find more at www.emsp.org.

Contact

For more information please contact claudiu.berbece@emsp.org or andreea.antonovici@emsp.org.