



Joint Action on Integration of ERNs into National Healthcare Systems – JARDIN

29th February 2024

More than 6,000 rare diseases (RD) are known to date. They are defined as diseases affecting no more than 5 in 10,000 people in Europe. Expertise and resources for these conditions are scarce. It is estimated that about 30 million people are living with a RD in Europe, making effective networking and cooperation measures for diagnosis and treatment essential.

In 2017, the EU therefore established the European Reference Networks (ERNs) which are a voluntary, coordinated cooperation between all member states in the field of highly specialised health services. These networks will generate immense added value for European citizens living with a RD or complex conditions. There are currently 24 networks connecting more than 1,600 clinical centres across the Union.

To improve the accessibility of the ERNs for patients in member states, the EU is now funding a pioneering 3-year project involving all member states plus Norway and Ukraine, the Joint Action on Integration of ERNs into National Healthcare Systems ('JARDIN'). JARDIN will be coordinated by Professor Till Voigtländer from the Medical University of Vienna in Austria and will produce recommendations, and implementation pilots in the main fields of action, such as patient pathways, national reference networks, and data management for rare diseases. These pilots constitute a promising way to provide EU member states with directly implementable solutions for their healthcare systems.

JARDIN's kick-off meeting is scheduled to take place in Brussels from 6th to 8th March 2024. It marks the beginning of a collaborative effort to shape the future of the ERNs.