

Discorso introduttivo - Cittadinanzattiva - 27 Febbraio 2018

“Cross border healthcare and centres of excellence to enhance patients’ rights: access, information and innovation”

Ladies and Gentlemen,

Welcome to the European Parliament, I am happy to open this conference today and I want to thank everybody for being here. Many thanks to Active Citizenship Network for continuing to support a common work and show the importance of patients’ rights in Europe.

In Europe, there are nearly 30 million people living with rare diseases and disorders. The EU and national governments are committed to improving the recognition and treatment of these rare and complex conditions by supporting cooperation and coordination at European level and providing guidance for national plans for rare diseases.

The European Directive of 2011 on the application of patients’ rights in cross-border healthcare provided a framework for the development of European Reference Networks between healthcare providers and Centres of Expertise in Member States, in particular in the area of rare diseases.

These Networks officially came into operation in March 2017 as virtual networks of healthcare providers across Europe. The main purpose of these networks is to improve clinical care for rare disease patients by, among other things, facilitating the pooling and exchange of knowledge and expertise as well as the development of guidelines in order to ensure equal access to precise information, appropriate and timely diagnoses and highly specialised and high-quality care for patients.

As underlined in June 2016 by the Health Ministers, in the conclusions of the Council of the European Union on Health and Consumer Affairs, the European Reference Networks present an opportunity for building capacity throughout Europe in the provision of specialised health services, in particular in the field of rare diseases, aiming at ensuring quality of care, and dissemination of knowledge and innovative practices.

I would like to insist on the importance to offer highly specialised training and continuous professional development for health professionals to continue to stimulate more innovative research on very rare diseases and to capture comparable and reliable data from connected patient registries, as well as other relevant information.

I am so happy that the Annual Work Programme 2018 of the Health Programme of the EU Commission-DG SANTE, confirmed high attention to this topic at EU level.

During the coming months, the Commission will publish the new proposal for the next Framework Programme (FP9), it will be an important occasion to accelerate knowledge and data integration, to develop e-health and to facilitate the access to European Health Platforms in order to improve the connection between patients and experts. I also support a FP9 more Mission oriented to face the challenges in health sector. I would like to point up that in Europe we still need to create a cross-border database infrastructure for a better use of health data and the new research program could offer this possibility.

In conclusion, I hope that the event will offer an open debate between civic and patient associations, experts, Institutional representatives to discuss about patients' rights and to find solutions to improve cross-border healthcare in Europe.

We can do more and it is important to continue to work together for a better European Healthcare system.

Thank you for your attention.