

SUMMARY OF THE NATIONAL WORKSHOP ON PATIENTS' RIGHTS AND RARE DISEASES

Date: 11 April 2024, Rome (in hybrid form)

In the context of enhancing the implementation of [Directive 2011/24/EU](#) on the application of patients' rights in cross-border healthcare (CBHC), the European Commission is organising ten national workshops, with the assistance of the [National Contact Points](#) established in all EU Countries. These workshops, whose location was identified following a call for expression of interest addressed to the members of the cross-border healthcare Expert Group, will be followed by a final EU-level event to be held in Brussels or Luxembourg in Spring 2025.

The objective of this action is twofold: to improve the information available at national level on the provisions included in the Directive, and to raise awareness in patients on their rights regarding the possibilities available to seek healthcare abroad, including for patients affected by a rare disease.

In this regard, the action is also aimed at raising awareness among the healthcare professionals about the possibilities of seeking the support of the 24 [European Reference Networks](#) (ERNs), which are cross-border networks that bring together European hospital centres of expertise and reference to tackle rare, low prevalence and complex diseases and conditions requiring highly specialised healthcare.

As regards the objective of improving the information available on cross-border healthcare and on the ERNs the European Commission is also working on improving the written communication materials to make it available at national level, in the languages of the EU countries where the national workshops will be organised. This work is funded by the [EU4Health](#) programme 2021-2027.

The national workshop organised by the Italian Ministry for Health, in collaboration with the European Commission, took place after the first one organised by the Maltese Ministry for Health and Active Ageing on 29 February, in occasion of the rare diseases' day. The audience included different stakeholder groups, such as healthcare professionals, regional healthcare providers, and patients' organisations; about 100 participants attended on site while about 400 followed the event online.

The workshop was opened by Giovanni Leonardi, Italian Ministry of Health, who emphasised the opportunity provided by the workshop to exchange experiences at the European, national, and regional levels to address the health needs of EU citizens better. He thanked the associations that support rare disease patients and their families, noting that Italy is currently implementing its 2023-2026 national plan on rare diseases.

Sandra Gallina, the European Commission's Director General for Health and Food Safety (DG SANTE) sent a welcome video message, in which she underscored that the CBHC Directive and the ERNs are milestones on the journey towards borderless healthcare.

During the workshop, comparative data on the Social Security Regulations (EC) No 883/04 and No 987/09 and Directive 2011/24/EU were illustrated, while the discussion focused on critical issues that EU citizens are facing when seeking healthcare abroad; on cross-border patient mobility and the European Health Data Space; on how to further the right to free movement of patients in the EU; on the European Commission's actions on rare diseases; on the operational functioning of ERNs and the Joint Action JARDIN; and on the ERNs from the perspective of Member States. The workshop saw also the testimony from a family member of a rare disease patient, and from the doctor who treated the patient; a presentation from a

patient organisation who illustrated the support offered to people with rare diseases, as well as a discussion with institutional and academic representatives and a presentation by the Commission on existing opportunities for cross-border cooperation and best practices. To conclude the round of presentations, some Italian regions presented their experiences on cross-border healthcare.

The Commission emphasised both the common commitment to improving healthcare for all patients and particularly those with rare diseases and the existing challenges, given that the organisation and provision of health services are a responsibility of the Member States. It was recognised that financial barriers prevent many patients to use the Directive and it was reiterated the strong political will at the European level to look at the situation.

The workshop stressed the invaluable role of the ERNs and cross-border health care options in bridging the gap for people with rare diseases. The financial burden faced by many patients and the complexity of national health care system and insurance policies were also emphasised. Finally, the workshops reaffirmed the importance of the continuation of investments in the European Reference Networks and their integration into national health systems.