

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

DATE: 29 FEBRUARY 2024 – MALTA IN HYBRID FORM

In the context of enhancing the implementation of [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare (CBHC), under the EU4Health programme, the European Commission with assistance of the National Contact Points, is customising and improving written communication materials and organising a series of 10 workshops at national level, culminating in an EU-level event in 2025. The location of the workshops was chosen as a result of interest expressed by EU Member States. The materials and workshops focus on patients' rights in cross-border healthcare, rare diseases, and [European Reference Networks](#) (ERNs).

The objective of the action is to raise awareness of patients' rights and to improve information on cross-border healthcare, thus facilitating the implementation of Directive 2011/24/EU, including the European Reference Networks, and their activities for patients affected by a rare disease.

The first national workshop was organised by the Maltese Ministry for Health and Active Ageing in collaboration with the European Commission and under the distinguished patronage of His Excellency the President of Malta. The workshop audience included different stakeholder groups, such as healthcare professionals, healthcare providers, health insurance, national/local administrations, and patients' organisations. 149 participants were present onsite and 162 people joined online.

The workshop was opened by Hon Mr Jo Etienne Abela, Malta's Minister for Health and Active Aging and by the European Commission. Sandra Gallina, the Commission's Director General for Health and Food Safety (DG Sante) sent a welcome video message.

The workshops had two main plenary sessions, which covered the topics of cross-border healthcare and the European Reference Networks for rare diseases. They also included testimonials from rare disease patients and their relatives that stimulated debate and discussion.

The afternoon was dedicated to three parallel sessions: Patients' Rights and Rare Diseases, ERNs and Rare Diseases Registries, and Cross-border Healthcare and eHealth.

The conclusion of 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.