

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

DATE: 17 JUNE 2024 – IRELAND IN HYBRID FORM

To enhance the implementation of [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare (CBHC), the Commission is organising 10 national workshops to raise awareness among patients and other stakeholders. In this context, under the [EU4Health](#) programme, communication materials on patients' rights in CBHC and the [European Reference Networks](#) (ERNs) on rare diseases have been prepared and are being distributed at the workshops.

After the workshops in Malta and in Italy on 29 February and 17 June, respectively, a third workshop took place in Dublin, organised and hosted by the Irish Health Service Executive (HSE) in collaboration with DG SANTE, the Commission's Directorate-General for Health and Food Safety and moderated by Tommie Gorman, journalist, the first patient in Ireland to access healthcare under the Regulations, and activist promoting the Directive (the Cross Border Directive, as it is known in Ireland). Approximately 60 participants attended on site while about 140 participants attended online.

The single-day workshop brought together Irish policy makers, representatives from national and local administrations, healthcare professionals, healthcare providers, health insurers, and patient organizations.

The workshop was opened by Micheál Martin, Ireland's Tánaiste (Deputy Prime Minister), Minister for Foreign Affairs & Minister for Defence, and former Minister for Health. Sandra Gallina, the Commission's Director General for Health and Food Safety (DG SANTE) sent a welcome video message.

During the workshop, participants heard about the Directive's importance in providing access to cross-border healthcare but stressed that some key challenges remain in recognizing its full potential.

The revised website was presented. The HSE.ie attracts about 35 million visits per year, with substantial traffic seeking healthcare schemes and allowances information. The HSE integrated 80 standalone websites into a single platform, where 80 % of people seeking information about CBHC are now finding the information they are seeking.

The 2003 report "In Sickness and in Debt" from the Irish Ombudsman was introduced followed by a presentation of the HSE on the follow up of the Ombudsman recommendations. A steering group has been formed to oversee the implementation of the 21 recommendations aimed at addressing various issues. These recommendations cover a range of actions, including the preparation of new content for the HSE website and the development of a revised application form for recipients of EU/EEA pensions. Additionally, a mechanism has been set up to allow referrers to rectify errors in their referrals. Furthermore, an appeals process, separate from the CBD office, is being established.

A scheme has been developed by PDFORRA, representing over 6 000 members across the Irish Defence Forces, encompassing a diverse demographic from recruits to retirees. One of its key initiatives, of the PDFORRA medical assistance scheme (PMAS), established in 2017 with a EUR 150 000 loan and EUR 1.50 weekly membership fees, is it enables members, families, and retirees to use the CBD to access healthcare by acting as guarantor for monies borrowed and assisting with any shortfalls.

The round table discussion included quality of care for patients, health service provision in Northern Ireland and the UK, delineation between national competence and that of the EU, the implementation

of the recommendations from the Irish Ombudsman, the low-level of awareness over patients' rights, financial challenges and innovative solutions and support mechanisms to alleviate these burdens.

The afternoon was dedicated to the European Reference Networks. ERNs play a crucial role, operating across different regions. They are evaluated periodically. Recently, grants have been structured into work packages, with seven mandatory packages covering coordination, dissemination, evaluation, the Clinical Patient Management System (CPMS), registries, data management and analysis, training and education, and clinical practice guidelines and decision support tools. Two voluntary work packages are dedicated to supporting activities for Ukraine.

The uptake of the ERNs in Malta was presented as a good practice. Malta has coordination agreements with all 24 ERNs.

Another presentation on ERNs stressed that currently 18 of the 24 ERNs are represented in Ireland. However, these networks face significant challenges. They rely on clinicians' voluntary dedication, administrative tasks, like outdated paperwork and data entry are burdensome.

To conclude the workshop, the Commission expressed its commitment to transform the healthcare landscape for all patients, and especially those with rare diseases. Participants were reminded to provide feedback on the communications materials that will guide all patients facing a rare disease and/or requiring cross-border healthcare treatment in making the best possible choice. Finally, it was highlighted that the workshops will culminate in an EU-side event in early 2025 where all interested parties are invited to attend.