

Workshop on Patients' Rights and Rare Diseases in the European Union

Date: Friday 26 September 2025

Time: 09:00 – 16:00

Venue: INSTITUT KLINICKÉ A EXPERIMENTÁLNÍ MEDICÍNY

Vídeňská 1958/9, 140 21 Praha 4

Agenda

Moderator: CZ Ministry of Health

09:00 – 09:30	Registration and welcome coffee
09:30 – 09:50	Welcome addresses <ul style="list-style-type: none">• CZ Minister of Health• European Commission - Directorate General for Health & Food Safety
	<u>Session 1: Patients' rights in cross-border healthcare</u>
09:50 – 10:25	Provision of Cross-border Healthcare services and healthcare prices <ul style="list-style-type: none">• European Commission• Institute of Economic Studies – Charles University
10:25 – 10:40	How is healthcare provided abroad reimbursed? What remains unseen by the patient? <ul style="list-style-type: none">• Health Insurance Fund
10:40 – 11:40	Panel discussion I: What are the main barriers to accessing healthcare services abroad? What are the possible solutions? <ul style="list-style-type: none">• Institute of Economic Studies – Charles University• CZ Ministry of Health• CZ Health Insurance Fund• European Commission• AT Hospital Management• NL Ministry of Health, Welfare and Sport• IE National Contact Point for CBHC
11:40 – 12:05	<i>Coffee break</i>
	<u>Session 2: Digital transformation of the healthcare sector</u>
12:10 – 12:25	European Health Data Space state of play How is patient's health data transmitted in cross-border situations? <ul style="list-style-type: none">• European Commission

12:25 – 12:45	What is an electronic cross-border prescription? How is it used in cross-border situations? <ul style="list-style-type: none">• CZ National eHealth Centre
12:45 – 13:00	Q & A
13:00 – 14:00	<i>Lunch break</i>
	<u>Session 3: European Reference Networks (ERN) for Rare Diseases</u>
14:00 – 14:15	The European Reference Networks in the European Union – general overview <ul style="list-style-type: none">• European Commission
14:15 – 14:30	Using Health Data to Improve Care for Patients with Rare Diseases <ul style="list-style-type: none">• CZ Ministry of Health• Institute of Health Information and Statistics of the Czech Republic
14:30 – 15:30	Panel discussion II: Standardised Data on Rare Diseases: The Key to Better Care <ul style="list-style-type: none">• CZ Ministry of Health• Institute of Health Information and Statistics of the Czech Republic• European Commission• CZ Patients' organisation• CZ Hospital Management• ERN member• ERN coordinator
15:30 – 15:45	Summary and final remarks of the day <ol style="list-style-type: none">1. Summary on cross-border healthcare2. Summary on ERNs
15:45 – 16:00	Closing remarks European Commission and CZ representative