



GOVERNMENT OF MALTA
MINISTRY FOR HEALTH
AND ACTIVE AGEING



CROSS-BORDER
Healthcare Malta



European
Reference
Networks

National Workshop on Patients' Rights and Rare Diseases

Date: Thursday 29th February 2024

Time: 08.30 am – 03.15pm

Venue: Mediterranean Conference Centre, Valletta

Agenda

8.30 – 9.00 am	Registration and welcome coffee
9.00 – 9.10 am	Opening speech by the <i>Hon Mr Jo Etienne Abela</i> Minister for Health and Active Aging
9.10 – 9.20 am	Speech by the EU Commission representative <i>Dr Giulio Gallo</i>
<u>Plenary Session 1: Cross-border Healthcare</u>	
<u>Chair Dr Anthony Gatt</u>	
9.20 – 9.40 am	Cross-border Healthcare and patients' rights <i>Dr Ewout van Ginneken</i>
9.40 – 9.50 am	Malta and Cross-Border healthcare <i>Dr Anthony Gatt</i>
9.50 – 10.00 am	Leading together for the mutual benefit of all - MyHealth@EU and Cross Border eHealth Services in Malta <i>Dr Stefan Buttigieg</i>
10.00 – 10.15 am	Q&A
10.15 - 10.45 am - Coffee break	
<u>Plenary Session 2: European Reference Networks and Rare Diseases</u>	
<u>Chair Dr James Clark</u>	
10.45 – 11.00 am	The European Reference Networks – Raising the bar for patients' with rare diseases and their healthcare providers across Europe <i>Dr James Clark</i>
11.00 – 11.10 am	Addressing rare diseases and ERNs <i>Dr Antonio González-Meneses</i>

11.10 – 11.20 am	Rare disease registries <i>Dr Stefanie Haeberle</i>
11.20 – 11.40 am	Experiencing a rare disease
11.40 – 11.55 am	Q&A

12.00 – 01.00 pm - Lunch & coffee

	<u>Session 3: Parallel sessions</u>
01.00 – 02.00 pm	<i>Break out rooms and parallel sessions:</i> Parallel session 1: Patients' Rights and Rare Diseases Panellists: <i>Dr Giulio Gallo, Ms Gertrude Buttigieg, Ms Rhoda Garland, Mr Oliver Scicluna</i> Parallel session 2: ERNs and Rare Diseases Registries Panellists: <i>Dr Antonio González-Meneses, Mr Stefano Vettorazzi, Dr Stefanie Haeberle, Dr Miriam Azzopardi, Ms Jeanette Scerri</i> Parallel session 3: Cross-border healthcare and eHealth Panellists: <i>Dr Ewout van Ginneken, Dr Anthony Gatt, Dr Stefan Buttigieg, Mr Jan Quintus Engelenburg</i>
02.15 – 03.00 pm	<u>Conclusions from the parallel sessions</u> <i>Chair: Dr Cristina Micallef</i> Summaries from the parallel sessions followed by a panel discussion
03.00 – 03.15 pm	Workshop Closure <i>Dr Giulio Gallo and Mr Walter Busuttil</i>