



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> <i>Chair Dr Anthony Gatt</i>
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

Plenary Session 2: European Reference Networks and Rare Diseases

Chair Dr James Clark

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 Gonzalez-Meneses</i>



11.10 – 11.20 am Rare disease registries
Dr Stefanie Haerberle

11.20 – 11.40 am Experiencing a rare disease

11.40 – 11.55 am Q&A

12.00 – 01.00 pm - Lunch & coffee

Session 3: Parallel sessions

01.00 – 02.00 pm *Break out rooms and parallel sessions:*

- **Parallel session 1: Patients' Rights and Rare Diseases**
Panellists: *Dr Giulio Gallo, Ms Gertrude Buttigieg, Ms Rhoda Garland, Mr Oliver Scicluna*
- **Parallel session 2: ERNs and Rare Diseases Registries**
Panellists: *Dr Antonio Gonzalez-Meneses, Mr Stefano Vettorazzi, Dr Stefanie Haerberle, Dr Miriam Azzopardi, Ms Jeanesse Scerri*
- **Parallel session 3: Cross-border healthcare and eHealth**
Panellists: *Dr Ewout van Ginneken, Dr Anthony Gatt, Dr Stefan Buttigieg, Mr Jan Quintus Engelenburg*

02.15 – 03.00 pm **Conclusions from the parallel sessions**

Chair: Dr Cristina Micallef

Summaries from the parallel sessions followed by a panel discussion

03.00 – 03.15 pm **Workshop Closure**

Dr Giulio Gallo and Mr Walter Busuttil