

Rare 2030 Panel of Experts

Membership List for Sub-Group 2: Data Collection and Utilisation*

Surname	First Name	Type of Stakeholder **	Country
Agius	Francis	National/Regional Competent Authority (National policy maker)	MT
Arzimanoglou	Alexis	ERN Coordinator/ERN Healthcare Provider representative	FR
Athanasiou	Dimitrios	Pharmaceutical Industry and other health-related industries	GR
Azzopardi	Miriam	National/Regional Competent Authority (National policy maker)	MT
Battye	Michelle	ERN Coordinator/ERN Healthcare Provider representative	UK
Benfredj	Rudy	Pharmaceutical Industry and other health-related industries	UK
Biller	Ruth	Patient advocate	DE
Blay	Jean-Yves	ERN Hospital Manager	FR
Buske	Orion	Individual Researcher	CA
Carraro	Vittoria	Pharmaceutical Industry and other health-related industries	BE
Castro	Raquel	Social care and social innovation experts	FR
Cisarik	Frantisek	National/Regional Competent Authority (National policy maker)	SK
Costello	Denis	Patient Advocate	ES
Dollfus	Hélène	ERN Coordinator/ERN Healthcare Provider representative	FR
Driessens	Mariette	Pharmaceutical Industry and other health-related industries	NL
Eichler	Hans-Georg	Regulatory Experts	NL
Evangelista	Teresinha	ERN Coordinator/ERN Healthcare Provider representative	FR
Evers	Pauline	Pharmaceutical Industry and other health-related industries	NL
Facchin	Paola	National/Regional Competent Authority (National policy maker)	IT

Galetti	Ilaria	Patient advocate	IT
Goodhand	Peter	International Initiatives	CA
Grentoft	Mette	Patient advocate	DK
Guardian	Marcus	HTA bodies/reimbursement authorities	NL
Haf Davies	Elin	Pharmaceutical Industry and other health-related industries	UK
Hans-Georg	Eichler	Regulatory Experts	NL
Harris	Tess	Patient advocate	UK
Hugon	Anne	Patient advocate	FR
Isla Gomez	Julián	Pharmaceutical Industry and other health-related industries	ES
Jacinto	Marta	Patient advocate	PT
Julkowska	Daria	European research networks and infrastructures	FR
Kolitsi	Zoi	Independent Researcher	GR
Le Borgne	Hélène	EU policy makers	BE
Le Cam	Yann	Individual expert involved in the European Joint Actions for Rare Diseases	BE
Lindgren	Peter	Health Economist	SE
Lindsell	Sarah	Individual Researcher	UK
Lopez Granados	Eduardo	ERN Coordinator/ERN Healthcare Provider representative	ES
Macek	Milan	National/Regional Competent Authority (National policy maker)	CZ
Magenheim	Rita	Patient Advocate	NL
Mañú - Pereira	Maria del Mar	ERN Coordinator/ERN Healthcare Provider representative	FR
Martin	Simona	EU policy makers	EC
Mathijssen	Irene	ERN Coordinator/ERN Healthcare Provider representative	NL
Meade	Nick	Patient advocate	UK
Montserrat Moliner	Antoni	Patient advocate	LUX

Natz	Alexander	Pharmaceutical Industry and other health-related industries	BE
O'Donnell	Peter	Journalist	BE
Olauson	Anders	International initiatives	SE
Palma	Ana	Pharmaceutical Industry and other health-related industries	BE
Petäjä	Jari	ERN Hospital managers	FI
Posada De La Paz	Manuel	Individual experts involved in the European Joint Actions for Rare Diseases	ES
Quinn	Casey	HTA bodies/reimbursement authorities	US
Rath	Ana	European research networks and infrastructures	FR
Richards	Tessa	Journalist	UK
Rigal	Loïc	Patient Advocate	FR
Sándor	János	National/Regional Competent Authority (National policy maker)	HU
Sangiorgi	Luca	ERN Coordinator/ERN Healthcare Provider representative	IT
Scollen	Serena	European research networks and infrastructures	UK
Severin	Emilia	National/Regional Competent Authority (National policy maker)	RO
Stedman	Ian	Individual Researcher	CA
Stevens	Sarah	Individual expert involved in the European Joint Actions for Rare Diseases	UK
Summar	Marshall	International initiatives	US
Taruscio	Domenica	International initiatives	IT
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	IT
Upadhyaya	Sheela	HTA bodies/reimbursement authorities	UK
van Zelst-Stams	Wendy	National/Regional Competent Authority (National policy maker)	NL
Verloes	Alain	ERN Coordinator/ERN Healthcare Provider representative	FR
Wagner	Thomas	ERN Coordinator/ERN Healthcare Provider representative	DE



Ward	Adrian	Pharmaceutical Industry and other health-related industries	CH
Wheeler	Russell	Patient advocate	UK
Wijnen	Rene	ERN Coordinator/ERN Healthcare Provider representative	NL
Wilson	Petra	Pharmaceutical Industry and other health-related industries	BE
Wulffraat	Nico	ERN Coordinator/ERN Healthcare Provider representative	NL
Yang	Rachel	International initiatives	CN
Ziemele	Baiba	Patient advocate	LV

(NB The following panel members were *assigned* to this group and may wish to change!)

Surname	First Name	Type of Stakeholder**	Country
Eichler	Hans-Georg	Regulatory Expert	NL
Pereira	Alberto	ERN Coordinator/ERN Healthcare Provider representative	NL
Schlender	Michael	Health Economist	DE

*The main headings under this sub-group include interoperability strategies, current and future roles of registries, FAIR data concepts, data linkage, Ethical and Legal considerations, etc

**Many people in this Panel of Experts belong to numerous categories – the ‘Type of Stakeholder’ listed against each name represents the *primary* capacity in which experts were invited to this Panel.