

Rare 2030 Panel of Experts

Membership List for Sub-Group 3: Availability and accessibility of Orphan Medical Products (OMPs) and medical devices*

Surname	First Name	Type of Stakeholder**	Country
Aleksovska (Stojmirova)	Vesna	Patient advocate	MK
Alves	Inês	Patient advocate	PT
Ardigò	Diego	Pharmaceutical Industry and other health-related industries	IT
Arellanesová	Anna	Patient advocate	CZ
Athanasiou	Dimitrios	Regulatory Experts	GR
Azzopardi	Miriam	National/Regional Competent Authority (National policy maker)	MT
Barić	Ivo	National/Regional Competent Authority (National policy maker)	HR
Bodemer	Christine	ERN Coordinator/ERN Healthcare Provider representative	FR
Bols	Thomas	Pharmaceutical Industry and other health-related industries	CH
Borras	Josep Maria	Individual Researcher	ES
Brectan	René	Patient advocate	CZ
Brunetta	Angelo Loris	Regulatory Experts	IT
Bruijns	Christel	Pharmaceutical Industry and other health-related industries	CH
Bucsics	Anna	HTA bodies/reimbursement authorities	AT
Carraro	Vittoria	Pharmaceutical Industry and other health-related industries	BE
Castro	Raquel	Social care and social innovation experts	FR
Cattaneo	Ivana	Pharmaceutical Industry and other health-related industries	IT

Chantelot	Emmanuel	Pharmaceutical Industry and other health-related industries	BE
Daly	Avril	Patient advocate	IE
Digneffe	Toon	Pharmaceutical Industry and other health-related industries	BE
Dooms	Marc	Individual Researcher	BE
Eichler	Hans-Georg	Regulatory Expert	NL
Evers	Pauline	Regulatory Experts	NL
Gatermann	Ruediger	Pharmaceutical Industry and other health-related industries	DE
Guardian	Marcus	HTA bodies/reimbursement authorities	NL
Guillot	Florence	International Initiatives	FR
Haf-Davies	Elin	Pharmaceutical Industry and other health-related industries	UK
Hivert	Virginie	Regulatory Experts	FR
Holm	Birthe Byskov	Patient advocate	DK
Hughes-Wilson	Wills	Pharmaceutical Industry and other health-related industries	UK
Incerti	Carlo	Pharmaceutical Industry and other health-related industries	NL
Ingeborg	Barisic	Individual expert involved in the European Joint Actions for Rare Diseases	HR
Isla Gomez	Julian	Regulatory Experts	ES
Jondeau	Guillaume	ERN Coordinator/ERN Healthcare Provider representative	FR
Konecna	Katerina	National/Regional Competent Authority (National policy Maker)	CZ
Le Cam	Yann	Individual expert involved in the European Joint Actions for Rare Diseases	BE
Lindgren	Peter	Health Economist	SE
Macchia	Flaminia	Pharmaceutical Industry and other health-related industries	BE
Magenheim	Rita	Patient Advocate	NL
Magrelli	Armando	Regulatory Experts	IT
Mann	Mirjam	Patient advocate	DE

Meade	Nick	Patient advocate	UK
Meszaros	Gergely	Patient advocate	HU
Mosca	Marta	ERN Coordinator/ERN Healthcare Provider representative	IT
Muthyala	Ramaiah	International initiatives	US
Nabbout	Rima	European research networks and infrastructures	FR
Natz	Alexander	Pharmaceutical Industry and other health-related industries	BE
O'Donnell	Peter	Journalist	BE
Palma	Ana	Pharmaceutical Industry and other health-related industries	BE
Parker	Samantha	Pharmaceutical Industry and other health-related industries	FR
Pirard	Vinciane	Pharmaceutical Industry and other health-related industries	BE
Quinn	Casey	HTA bodies/reimbursement authorities	US
Richards	Tessa	Journalist	UK
Rigal	Loïc	Patient Advocate	FR
Rui Santos	Ivo	Regulatory Experts	PT
Sangiorgi	Luca	ERN Coordinator/ERN Healthcare Provider representative	IT
Sepodes	Bruno	Regulatory Experts	PT
Spink	Jayne	Patient advocate	UK
Sproedt	Claudia	Patient advocate	DE
Stefanov	Rumen	National/Regional Competent Authority (National policy maker)	BG
Stoyanova-Beninska	Violeta	Regulatory Experts	NL
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	IT
Ussi	Anton	European research networks and infrastructures	NL
van Doorne	Cathelijne	Patient advocate	BE
van Weely	Sonja	European research networks and infrastructures	NL



Ward	Adrian	Pharmaceutical Industry and other health-related industries	CH
Wheeler	Russell	Patient advocate	UK
Wong-Rieger	Durhane	International initiatives	CA
Yang	Rachel	International Initiatives	CH
Zamorska	Tetiana	Patient advocate	UA
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
Moll	Nathalie	Pharmaceutical Industry and other health-related industries	BE
Schlander	Michael	Health Economist	DE
Straus	Sabine	Regulatory Experts	NL

*items under this heading include HTA, pricing, supplements, repurposing; public-private partnerships

**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.