

Rare 2030 Panel of Experts

Membership List for Sub-Group 7:

'Patient Partnerships: engagement, empowerment and patient-centred approaches to Rare Disease issues'

Surname	First Name	Type of Stakeholder*	Country
Andrew	Mandy	Social care and social innovation experts	UK
Antoniou	Eleni	Patient advocate	CY
Ardigò	Diego	Pharmaceutical Industry and other health-related industries	IT
Asikainen	Katri	Patient Advocate	FI
Azzopardi	Miriam	National/Regional Competent Authority (National policy maker)	MT
Bauwens	Lieven	Patient advocate	BE
Bellagambi	Simona	Patient advocate	IT
Berkholz	Dieter	National/Regional Competent Authority (National policy maker)	DE
Bloom	Lara	Patient advocate	UK
Brectan	René	Patient advocate	CZ
Bros-Facer	Virginie	European research networks and infrastructures	FR
Brüggmann	Petra	Patient advocate	DE
Butterworth	Sondra	Individual Researcher	UK
Carraro	Vittoria	Pharmaceutical Industry and other health-related industries	BE
Cattaneo	Ivana	Pharmaceutical Industry and other health-related industries	IT
Costello	Denis	Patient Advocate	ES
Dan	Dorica	Patient advocate	RO

Dedeu	Toni	Health Economist	UK
Dollfus	Hélène	ERN Coordinator/ERN Healthcare Provider representative	FR
Driessens	Mariette	Regulatory Experts	NL
Eleftheriou	Androulla	Patient advocate	CY
Feider-Rohen	Shirley	Patient advocate	LU
Fonfria Solabarrieta	Marta	Social care and social innovation experts	ES
Gatermann	Ruediger	Pharmaceutical Industry and other health-related industries	DE
Grentoft	Mette	Patient advocate	DK
Gschmeidler	Brigitte	Social care and social innovation experts	AT
Haf-Davies	Elin	Pharmaceutical Industry and other health-related industries	UK
Harris	Tess	Patient advocate	UK
Hivert	Virginie	Regulatory Experts	FR
Holm	Birthe Byskov	Patient advocate	DK
Holtgrewe	Ursula	Social care and social innovation experts /health economist	AT
Holzer	Ulrike	Patient advocate	AT
Hughes-Wilson	Wills	Pharmaceutical Industry and other health-related industries	UK
Hugon	Anne	Patient advocate	FR
Jain	Ritu	International initiatives	SG
João Freitas	Maria	Social care and social innovation experts	PT
Konecna	Katerina	National/Regional Competent Authority (National policy Maker)	CZ
Krutzinna	Jenny	Individual Researcher	NO
Lindsell	Sarah	Individual Researcher	UK
Merkel	Bernard	EU policy makers	UK
Meszaros	Gergely	Patient advocate	HU
Mohr	Lisen Julie	Social care and social innovation experts	NO

Montefusco	Maria	Patient advocate	SE
Mosca	Marta	ERN Coordinator/ERN Healthcare Provider representative	IT
Nabbout	Rima	European research networks and infrastructures	FR
O'Connor	Daniel	Regulatory Experts	UK
Parier	Eve	ERN Hospital Manager	FR
Parker	Samantha	Pharmaceutical Industry and other health-related industries	FR
Plura	Marek	EU policy makers	PL
Popova	Jana	Patient Advocate	BE
Prats Monné	Xavier	EU policy makers	BE
Quinn	Casey	HTA bodies/reimbursement authorities	US
Scollen	Serena	European research networks and infrastructures	UK
Sepodes	Bruno	Regulatory Experts	PT
Scopinaro	Annalisa	Patient advocate	IT
Slater	Graham	Patient advocate	UK
Sproedt	Claudia	Patient advocate	DE
Tvedt Skarberg	Rebecca	Patient advocate	NO
Upadhyaya	Sheela	HTA bodies/reimbursement authorities	UK
Voigtlaender	Till	National/Regional Competent Authority (National policy maker)	AT
Wagener	Yolande	National/Regional Competent Authority (National policy maker)	LU
Wagner	Thomas	ERN Coordinator/ERN Healthcare Provider representative	DE
Walani	Salimah	Patient advocate	US
Weinman	Ariane	Patient advocate	FR
Widenmann-Grolig	Anke	Patient advocate	DE
Yang	Rachel	International initiatives	CH
Ziemele	Baiba	Patient advocate	LV



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Zmazek	Vlasta	Patient advocate	HR
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(NB The following panel members were *assigned* to this group and may wish to change!)

Surname	First Name	Type of Stakeholder**	Country
Miasnikova	Irina	Patient advocate	RU
Zhang	Shuyang	International Initiatives	CN

* 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.