

## Rare 2030 Panel of Experts

### Membership List for Sub-Group 1: 'Political & strategic frameworks relevant to Rare Diseases'\*

Surname	First Name	Type of Stakeholder **	Country
Agius	Francis	National/Regional Competent Authority (National policy maker)	MT
Aleksovska (Stojmirova)	Vesna	Patient advocate	MK
Anastasiadou	Violetta	National/Regional Competent Authority (National policy maker)	CY
Ancochea	Alba	Patient advocate	ES
Andersen	Terkel	Patient advocate	DK
Andrew	Mandy	Social care and social innovation experts	UK
Antoniou	Eleni	Patient advocate	CY
Are Aksnes	Stein	National/Regional Competent Authority (National policy maker)	NO
Arzimanoglou	Alexis	ERN Coordinator/ERN Healthcare Provider representative	FR
Athanasiou	Dimitrios	Regulators	GR
Azzopardi	Miriam	National/Regional Competent Authority (National policy maker)	MT
Battye	Michelle	ERN Coordinator/ERN Healthcare Provider representative	UK
Balfour	Jo	Patient advocate	UK
Baynam	Gareth	International initiatives	AU
Benfredj	Rudy	Pharmaceutical Industry and other health-related industries	UK
Bellagambi	Simona	Patient advocate	IT
Berkholz	Dieter	National/Regional Competent Authority (National policy maker)	DE



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Biller	Ruth	Patient advocate	DE
Blay	Jean-Yves	ERN Hospital Manager	FR
Bols	Thomas	Pharmaceutical Industry and other health-related industries	CH
Borras	Josep Maria	Individual Researcher	ES
Brectan	René	Patient advocate	CZ
Brügmann	Petra	Patient advocate	DE
Brunetta	Angelo Loris	Regulators	IT
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
Cisarik	František	National/Regional Competent Authority (National policy maker)	SK
Dedeu	Toni	Health Economist	UK
Eleftheriou	Androulla	Patient advocate	CY
Facchin	Paola	National/Regional Competent Authority (National policy maker)	IT
Feider	Shirley	Patient advocate	LU
Feitz	Wout	ERN Coordinator/ERN Healthcare Provider representative	NL
Fonfria	Marta	Social care and social innovation experts	ES
Fonseca	Valter	National/Regional Competent Authority (National policy maker)	PT
Guardian	Marcus	HTA bodies/reimbursement authorities	NL
Guillot	Florence	International Initiatives	FR
Holm	Birthe Byskov	Patient Advocate	DK



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Hughes-Wilson	Wills	Pharmaceutical Industry and other health-related industries	UK
Incerti	Carlo	Pharmaceutical Industry and other health-related industries	NL
Julkowska	Daria	European research networks and infrastructures	FR
Kolitsi	Zoi	Independent Researcher	GR
Kotulska-Józwiak	Katarzyna	National/Regional Competent Authority (National policy maker)	PL
Krutzinna	Jenny	Individual Researcher	NO
Le Borgne	Hélène	EU policy makers	EC
Lindgren	Peter	Health Economist	SE
Lindsell	Sarah	Individual Researcher	UK
Macek	Milan	National/Regional Competent Authority (National policy maker)	CZ
McKay	Lucy	Individual Researcher	UK
Malniece	Ieva	Individual Researcher	LV
Mañú Pereira	Maria del Mar	ERN Coordinator/ERN Healthcare Provider representative	FR
Mann	Mirjam	Patient advocate	DE
Martin	Simona	EU Policy Makers	IT
Mathijssen	Irene	ERN Coordinator/ERN Healthcare Provider representative	NL
Melegh	Bela	Individual experts involved in the European Joint Actions for Rare Diseases	HU
Merkel	Bernard	EU Policy Makers	UK
Mohr	Lisen Julie	Social care and social innovation experts	NO
Montefusco	Maria	Patient advocate	SE
Montserrat Moliner	Antoni	Patient advocate	LU
Natz	Alexander	Pharmaceutical Industry and other health-related industries	BE
O'Connor	Daniel	Regulators	UK
O'Donnell	Peter	Journalist	BE

Oosterwijk	Cor	Patient advocate	NL
Palma	Ana	Pharmaceutical Industry and other health-related industries	BE
Parier	Eve	ERN Hospital managers	FR
Petäjä	Jari	ERN Hospital managers	FI
Pirard	Vinciane	Pharmaceutical Industry and other health-related industries	BE
Plura	Marek	EU policy makers	PL
Pogany	Gabor	Patient advocate	HU
Prats Monné	Xavier	EU Policy Makers	BE
Rigal	Loïc	Patient Advocate	FR
Sándor	János	National/Regional Competent Authority (National policy maker)	HU
Schoeters	Eva	Patient advocate	BE
Schuster	Ralph	European research networks and infrastructures	DE
Scopinaro	Annalisa	Patient advocate	IT
Sepodes	Bruno	Regulators	PT
Severin	Emilia	National/Regional Competent Authority (National policy maker)	RO
Slater	Graham	Patient advocate	UK
Spink	Jayne	Patient advocate	UK
Stefanov	Rumen	National/Regional Competent Authority (National policy maker)	BG
Stevens	Sarah	Individual expert involved in the European Joint Actions for Rare Diseases	UK
Stewart	Rebecca	Patient Advocate	UK
Stoyanova-Beninska	Violeta	Regulators	NL
Taruscio	Domenica	National/Regional Competent Authority (National policy maker)	IT
Tomov	Vladimir	Patient advocate	BG

Toon	Digneffe	Pharmaceutical Industry and other health-related industries	BE
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	IT
Treacy	Eileen	National/Regional Competent Authority (National policy maker)	IE
Tumiene	Birute	National/Regional Competent Authority (National policy maker)	LT
Valdmane	Antra	National/Regional Competent Authority (National policy maker)	LV
van Weely	Sonja	European research networks and infrastructures	NL
van Zelst-Stams	Wendy	National/Regional Competent Authority (National policy maker)	NL
Voigtlaender	Till	National/Regional Competent Authority (National policy maker)	AT
Wagener	Yolande	Patient advocate	LU
Walani	Salimah	Patient advocate	US
Ward	Adrian	Pharmaceutical Industry and other health-related industries	CH
Weinman	Ariane	Patient advocate	FR
Wheeler	Russell	Patient advocate	UK
Widenmann-Grolig	Anke	Patient advocate	DE
Wilson	Petra	Pharmaceutical Industry and other health-related industries	BE
Wijnen	Rene	ERN Coordinator/ERN Healthcare Provider representative	NL
Wong-Rieger	Durhane	International initiatives	CA
Zamorska	Tetiana	Patient advocate	UA

\*The main headings under this sub-group include EU frameworks & policies; national plans & strategies for RD, NP for genomics, 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.