

## Rare 2030 Panel of Experts

### Membership List for Sub-Group 6: Integrated, social and holistic care for people with rare diseases \*

| Surname           | First Name | Type of Stakeholder**   | Country |
|-------------------|------------|---|---------|
| 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      |
| Arellanesová      | Anna       | Patient advocate  | CZ      |
| 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      |
| Bloom             | Lara       | Patient advocate  | UK      |
| Bodemer           | Christine  | ERN Coordinator/ERN Healthcare Provider representative        | FR      |
| Borras            | Josep M    | Individual Researcher   | ES      |
| Butterworth       | Sondra     | Individual Academic   | UK      |
| Chantelot         | Emmanuel   | Patient advocate  | BE      |
| Carraro           | Vittoria   | Pharmaceutical Industry and other health-related industries   | BE      |
| D'Amato Sizonenko | Loredana   | Patient advocate  | CH      |
| Dan               | Dorica     | Patient advocate  | RO      |
| Dedeu             | Toni       | Social care and social innovation experts                     | UK      |
| Dollfus           | Hélène     | ERN Coordinator/ERN Healthcare Provider representative        | FR      |

|                 |             |   |    |
|-----------------|-------------|---|----|
| Feider          | Shirley     | Patient advocate  | LU |
| Fonfria         | Marta       | Social care and social innovation experts                                   | ES |
| Freitas         | Maria João  | Social care and social innovation experts                                   | PT |
| Galetti         | Ilaria      | Patient advocate  | IT |
| Gatermann       | Ruediger    | Pharmaceutical Industry and other health-related industries                 | DE |
| Graessner       | Holm        | ERN Coordinator/ERN Healthcare Provider representative                      | DE |
| Gschmeidler     | Brigitte    | Social care and social innovation experts                                   | AT |
| Guillén-Navarro | Encarna     | Social care and social innovation experts                                   | ES |
| Holzer          | Ulrike      | Patient advocate  | AT |
| Jain            | Ritu        | International initiatives   | SG |
| Konecna         | Katerina    | National/Regional Competent Authority (National policy Maker)               | CZ |
| Kolitsi         | Zoi         | Individual Researcher   | GR |
| Krutzinna       | Jenny       | Individual Researcher   | NO |
| Macchia         | Flaminia    | Pharmaceutical Industry and other health-related industries                 | BE |
| Meszaros        | Gergely     | Patient advocate  | HU |
| Mohr            | Lisen Julie | Social care and social innovation experts                                   | NO |
| Montefusco      | Maria       | Patient advocate  | SE |
| Özbek           | Uğur        | Individual Researcher   | TR |
| Parier          | Eve         | ERN Hospital Manager  | FR |
| Plura           | Marek       | EU policy makers  | PL |
| Pogany          | Gabor       | Patient advocate  | HU |
| Popova          | Jana        | Patient Advocate  | BU |
| Posada          | Manuel      | Individual experts involved in the European Joint Actions for Rare Diseases | ES |
| Prats Monne     | Xavier      | EU policy makers  | BE |
| Rath            | Ana         | European research networks and infrastructures                              | FR |
| Scopinaro       | Annalisa    | Patient advocate  | IT |
| Stefanov        | Rumen       | National/Regional Competent Authority (National policy maker)               | BG |



|                  |           |   |    |
|------------------|-----------|---|----|
| Stewart          | Rebecca   | Patient Advocate  | UK |
| Tomov            | Vladimir  | Patient advocate  | BG |
| Tvedt Skarberg   | Rebecca   | Patient advocate  | NO |
| Verloes          | Alain     | ERN Coordinator/ERN Healthcare Provider representative        | FR |
| Wagener          | Yolande   | Patient advocate  | LU |
| Waszczuk         | Antonina  | Social care and social innovation experts                     | DE |
| Widenmann-Grolig | Anke      | Patient advocate  | DE |
| Wilson           | Petra     | Pharmaceutical Industry and other health-related industries   | BE |
| Wulfraat         | Nico      | ERN Coordinator/ERN Healthcare Provider representative        | NL |
| Zerjav Tanšek    | Mag Mojca | National/Regional Competent Authority (National policy maker) | SI |
| Zmazek           | Vlasta    | Patient advocate  | HR |

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

| Surname      | First Name | Type of Stakeholder**   | Country |
|--------------|------------|---|---------|
| Daly         | Avril      | Patient advocate  | IE      |
| Miasnikova   | Irina      | Patient advocate  | RU      |
| Schlander    | Michael    | Health Economist  | DE      |
| Voigtlaender | Till       | National/Regional Competent Authority (National policy maker) | AT      |
| Zhang        | Shuyang    | International Initiatives                                     | CN      |

\*This subgroups includes topics such as polices to integrate health and social care, integrated care models; assessments of functioning; social research; helplines, information, 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.