



# How to develop clinical research in a network environment

## Workshop 3

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## 3. How to develop clinical research in a network environment

- Facilitator: Irene Glinos
- Experts:
  - Silvia Deandra, Joint Research Center, European Commission
  - Pascale Flamant, UNICANCER
  - Mauricio Scarpa, Brains for Brain Foundation
  - Samantha Parker, Lysogene
  - Denis Lacombe, EORTC
- Rapporteur: Ian Jones



# 3. How to develop clinical research in a network environment

## Programme

- **Opening**
- **Clinical Research in a network environment**
  - Introductory presentations
    - JRC registries project and potential interaction with ERNs - Silvia Deandra, Joint Research Center, European Commission
    - Software for identification of patients for clinical research - Ms Pascale Flamant, UNICANCER
    - Integrating clinical research in the care environment of ERNs - Mauricio Scarpa, Brains for Brain Foundation (expert in clinical trials in rare diseases)
    - SPECTArare as an innovative model of combining clinical research and care in an ERN - Denis Lacombe, EORTC
    - What framework is needed to collaborate with industry? - Samantha Parker, Lysogene
  - Group discussion + Feed-back
- **Conclusion**



# 3. How to develop clinical research in a network environment

## 3.1 Clinical Research in a network environment

- Discuss how you would develop a clear vision and agenda for clinical research in your network
  - How would you determine and review priorities for the network?
  - What are the challenges and potential benefits of doing this within the context of thematic networks (of groups of rare, low prevalence and complex diseases)?
  - What level of resources (human, technical, physical) would network members be expected to make available to support research activities and clinical trials (structure for clinical research)?
  - How would you link clinical research with care?
  - What are the specific challenges for turning existing European research networks into an ERN?
  - How should collaboration with industry be envisaged and organised?

# A model for the purposes of grouping RD thematically

<b>Rare immunological and auto-inflammatory diseases</b>
<b>Rare bone diseases</b>
<b>Rare cancers* and tumours</b>
<b>Rare cardiac diseases</b>
<b>Rare connective tissue and musculoskeletal diseases</b>
<b>Rare malformations and developmental anomalies and rare intellectual disabilities</b>
<b>Rare endocrine diseases</b>
<b>Rare eye diseases</b>
<b>Rare gastrointestinal diseases</b>
<b>Rare gynaecological and obstetric diseases</b>
<b>Rare haematological diseases</b>

**Rare craniofacial anomalies and ENT disorders**

**Rare hepatic diseases**

**Rare hereditary metabolic disorders**

**Rare multi-systemic vascular diseases**

**Rare neurological diseases**

**Rare neuromuscular diseases**

**Rare pulmonary diseases**

**Rare renal diseases**

**Rare skin disorders**

**Rare urogenital diseases**

\*Note: The networking of rare cancers is currently under discussion in EC Expert Group on Cancer Control.