



## Parallel session PS2: Quality assessment, monitoring and evaluation of the networks:

21 November 15:20 – 17:05

<p><b>Session leaders:</b></p> <ul style="list-style-type: none"> <li>✓ <b>Chris Chapple &amp; Michelle Battye</b>, ERN EUROGEN</li> <li>✓ <b>Enrique Terol</b>, DG SANTE B3</li> </ul>	<p><b>Chair:</b></p> <ul style="list-style-type: none"> <li>✓ <b>Chris Chapple</b>. ERN EUROGEN Coordinator and Speaker of the Working Group on continuous monitoring and quality improvement of the ERNs</li> </ul>
<p><b>Speakers:</b></p> <ul style="list-style-type: none"> <li>✓ Michelle Battye, ERN EUROGEN</li> <li>✓ Enrique Terol, Unit B3 DG SANTE</li> <li>✓ Jason GAVIN , Unit A4 DG SANTE</li> <li>✓ Annalisa Trama/Simon Oberst, Joint Action on Rare Cancers (JARC)</li> <li>✓ Laura Marin, Board of Member States, Spain</li> <li>✓ Ruben Diaz, European Children's Hospitals Organisation (ECHO)</li> </ul>	<p><b>EC support official:</b></p> <ul style="list-style-type: none"> <li>✓ Christophe Kusendila. Unit B3 DG SANTE</li> </ul>

### Aim of the parallel session:

- Present the ongoing work on ERNs continuous monitoring and quality improvement system including presenting the initial set of 18 ERN common indicators which can be used to assess the key performance of all the ERNs.
- Demonstrate how the monitoring system IT solution can capture data to show the added value of the ERNs.
- Present a roadmap for the period 2019-2021 and the project to develop an integrated ERN Assessment, Monitoring , Evaluation an Quality Improvement System (AMEQIS)
- Explore how Member States and ERN healthcare providers can help verify the expertise of the ERN healthcare providers and assist with data collection
- Discuss the link and synergies of the hospital clinical data and outcome measures management and the ERNs monitoring and evaluation system

### **Main issues to be addressed:**

- Set the context: need for an ERN monitoring system, the Working Group on Monitoring and Quality Improvement (ERN CG and BoMS).
- Presentation of 18 ERN common indicators, each linking to high level objectives of ERNs
- Presentation of IT tool to capture the data and demonstration of how it works
- The need of identifying disease specific outcome indicators by ERN
- Show how the monitoring system will feed into the evaluation of the ERNs every 5 years
- Present the ongoing work on rare cancer outcome indicators developed by the Joint Action on Rare Cancers (JARC)
- The role and synergies between the ERNs, the Member States and the Hospital Managers in the implementation of an ERNs Information System.

### **Format of the session:**

- Presentations
- Question and answer session