



*Istituto Oncologico  
del Mediterraneo  
March 26<sup>th</sup>-27<sup>th</sup>  
2019*

Via Penninazzo, 11  
Viagrande - Catania



Organisation  
of European  
Cancer Institutes

European Economic  
Interest Grouping



Istituto Oncologico  
del Mediterraneo s.p.a.



# WP5 CONSENSUS MEETING

## ORGANISING SECRETARIAT

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The EU Joint Action on Rare Cancers is the natural framework for all stakeholders to work together to:

- prioritise rare cancer, in the agenda of the EU and Member States, with a view to national cancer plans and quality of healthcare, harmonization of clinical practice, innovation through promotion of clinical and translational research;
- develop innovative and shared solutions, mainly to be implemented through the future ERNs on rare cancers, in the areas of quality of care, research, education and state of the art definition on prevention, diagnosis and treatment of rare cancers.

The JARC WP5 Plenary Consensus Conference aims to agree sets of Quality Standards to recommend for Cancer European Reference Networks (ERNs) and for National Rare Cancer Networks, as a basis for evaluation, monitoring and quality improvement and to come to (or close to) a consensus on quantitative indicators in cancer for those two groups, and to discuss self-assessment and independent assessment mechanisms.



## PROGRAMME

### Monday 25<sup>th</sup> March

Arrival of the participants - Free time and dinner

### Tuesday 26<sup>th</sup> March

08.00 Departure by bus to the Istituto Oncologico del Mediterraneo –  
The busses stop in front of the “Mercure Hotel Catania Excelsior”  
and “Palace Catania - UNA Esperienze” Hotel

08.45 **Welcome and Objectives of the meeting**

- Objectives of this meeting – **Simon Oberst**
- Outputs of the JARC relevant to WP5  
**Paolo Casali & Annalisa Trama**
- The two levels of output for WP5  
the Cancer ERNs and National Networks in formation  
**Simon Oberst**

09.30 **European Reference Networks (ERNs)**

- AMEQUIS and the work of the ERN Monitoring group
- Video of Enrique Terol (ERN Conference)  
**Michelle Battye**

### 10.15 Coffee break

11.00 **Consensus Session 1**

- Draft Quality Standards on Governance and Co-ordination,  
and on Patient-centeredness and patient empowerment

### 13.00 Lunch

14.00 **Consensus Session 2**

- Draft Quality Standards on Multi-disciplinarity, Quality control and  
Infrastructure

### 16.00 Coffee Break

16.15 **Consensus Session 3**

- Draft Quality Standards on Research, Education and Training,  
and Networking

18.00 End of first day and Departure by busses to the Hotels

19.30 Departure to the Conference Dinner at the Restaurant  
“Me cumpari Turiddu” (walking distance)

### Wednesday 27<sup>th</sup> March

8.00 Departure by bus to the Istituto Oncologico del Mediterraneo

8.45 Summary of 1<sup>st</sup> Day and issues raised – **Simon Oberst**

9.00 **Quantitative indicator consensus Session**

- the 18 agreed indicators from ERN working group  
**Michelle Battye**
- a shortlist for Rare Cancer ERNs

### 10.30 Coffee break

11.00 **Quantitative indicator consensus Session** (cont.)

12.00 **Discussion**

- self-assessment and external assessment processes  
(especially at National Level) – chair **Simon Oberst**

### 13.00 Lunch and Close of the Conference

Free time

### 14.30 Departure by bus to the Catania airport