WP5 CONSENSUS MEETING

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 25th March
Arrival of the participants - Free time and dinner

Tuesday 26th 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
- Cancer ERNs’ approach to Quality – EURACAN
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 27th March
8.00 Departure by bus to the Istituto Oncologico del Mediterraneo
8.45 Summary of Day 1st and issues raised – Simon Oberst
9.00 Quantitative indicator consensus Session
- the 18th 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