

# WP5 Quality Assurance

## What have we achieved?

### Quality Standards

- We have achieved a 6th draft of the Quality Standards for Rare Cancer Networks, which have received input from:
  - Associated Partners in the JARC, EURACAN, Eurordis, ECPC and others
- We have designed standards 2 sets:
  1. One for the 3 Cancer ERNs which are consistent with ERN Operational Criteria
  2. A fuller set which can voluntarily be applied to National Networks where their majority of Rare Cancer patients are treated.

# Intended use of the Standards for Rare Cancer Networks (Endpoint)

- We want to work with the ERN monitoring group so that the Core Standards (or an adaptation) will be adopted for the cancer ERNs
- A second, fuller, set of standards would be 'advisory' or 'good practice' for National/Regional Rare Cancer Networks

The standards proposed are general enough to adapt to many different situations, and make them suitable to many different countries.



We performed a literature review on existing care networks worldwide, and also an in-depth comparative study of other Cancer accreditation standards

We studied and analysed the following Quality Standards in depth before drafting our proposals for Rare Cancer Networks:

- OECI Quality Standards
- German Cancer Society (Deutsche Krebsgesellschaft)
- INCa (National Cancer Standards in France)
- ERN application (2016 Operational Criteria)
- ENETS quality standards for the network of Neuro-Endocrine Tumours



## Domains of the JARC – proposed Standards try to mirror the chapters of the ERN Assessment Manual – Operational Criteria

- Governance and Co-ordination
- Patient empowerment and patient-centred care
- Multidisciplinary approach
- Good Practice, Outcome Measures and Quality Control
- Research
- Education, training and development
- Networking and collaboration
- Facilities, equipment and infrastructure



## Question: What Standards for Evaluation will the EU want to use every 5 years?

The Commission's Implementing Decision of March 2014, Article 14 states that ERNs shall be periodically evaluated every five years by an evaluation body that shall draw an evaluation report for the Commission, the ERN members and the BoMs.

Presumably this evaluation needs to measure improvement/effectiveness:

The JARC is proposing for Cancer ERNs:

- 47 Quality Standards, of which around 35 need to be fulfilled at HCP level
- These Standards can be adapted to all ERNs in Rare Diseases.

These JARC standards are an adaptation and an extension of the initial Operational Criteria:

- The Network (69 'measures'/standards)
- Each HCP (55 'measures/standards')



## Quantitative Indicators

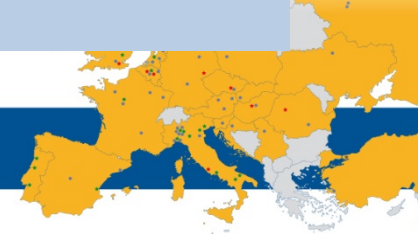
- The ERN Monitoring Group is proposing a generic set of 18 indicators to be streamed annually from the Co-ordinators and HCPs
- The JARC is proposing a further set of indicators which are more Cancer-specific:
  - Between 11 and 23 (depending on whether we are focusing on just CPMS patients or all rare cancer patients treated)
  - Some of these indicators could just be for internal use of the 3 cancer ERNs



## Questions to ask you regarding Cancer ERNs (both Commission and Member States)

1. Can you confirm that you want us to define standards for the whole network including the HCPs (or solely on the effectiveness of the ERN co-ordination).
2. Can you confirm that you want us to define standards and collect data on all patients treated in the ERN (not just that minority of patients who become ERN Network Patients through the CPMS)?

Another way of phrasing these questions is: How interested is the ERN Monitoring Group and the Member States in having a complete picture of Rare cancers in Europe and the quality of their diagnosis and treatment (including consistency among the HCPs?)[but NB the Operational Criteria for the Assessment of Healthcare providers]



## Final Question

The Commission's Implementing Decision of March 2014, Article 14 states that ERNs shall be periodically evaluated every five years by an evaluation body that shall draw an evaluation report for the Commission, the ERN members and the BoMs.

What does the EU envisage as the 5 year Evaluation Programme/System for the ERNs?

Suggestions:

1. Evaluate the ERN, but visit the HCPs only on a selected basis
2. **Put great emphasis on Improvement Plans**

