



A multi-stakeholder partnership initiative

10 February 2012



European Society for Medical Oncology



European Society for Medical Oncology (ESMO)
Rare Tumors in Europe: Challenges and Solutions
6 November 2008 - Hotel Renaissance, Brussels

39 recommendations on stakeholder actions and public policies:

» 8 addressing regulatory barriers in rare cancer care

» 11 addressing barriers to patients' access to care

» 6 addressing methodological barriers to rare cancer care

» 2 on education of healthcare professionals

» 9 addressing the need for centres of expertise and European reference networks

» 3 on access to information on rare cancers

→ Rare Cancers Europe Cooperating Organisations



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➔ Implementation of 39 political recommendations on stakeholder actions and public policies

Goal 1

Improve the methodology of clinical studies in rare cancers

Goal 2

Improve the organisation of health care in rare cancers

Goal 3

Improve access of rare cancer patients to new therapies in the EU

Strategic focus

- ◆ Develop scientific-based platforms
- ◆ Gather scientific findings
- ◆ Build consensus among professionals and the patient advocacy community
- ◆ Educate and raise awareness with target audiences
- ◆ Advocate recommendations for political and stakeholder implementation

Goal 1

Activities

1. 2011-2012: Consensus disc. and conference / consensus meeting on the methodology of clinical research on rare cancers (oncologists, bio-statisticians, researchers, regulators, nurses, patient advocacy groups, ...)
2. 2012: Advocacy activities (EU & MS regulatory authorities)

Deliverables

1. Conference / consensus meeting (9/10 February 2012) and pre-document
2. Scientific meeting report / consensus paper
3. Publication of report / paper (Annals of Oncology or else)
4. Set of advocacy materials for national adaptation

Measures of success

1. Publication of meeting report / consensus paper
2. Number of studies by cooperative groups and pharma industry after 5 years and number of patients recruited
3. Changes in the clinical trials environment

Improve the methodology of clinical research on rare cancers



Goal 2

Activities *

1. 2011-2012: European rare cancer-related surveys on collaborative networks and EU National plans and on existing Clinical Guidelines
2. 2012: 2 meetings to develop consensus guidelines (TBD)
3. 2012: Advocacy activities with network leaders for guideline implementation

Deliverables

1. Publication of survey results (Annals of Oncology or else)
2. Consensus guidelines for quality criteria of collab. networks on health care of rare cancer patients
3. Documentation of exist. Clin. Practice Guidelines on one or more rare cancers in Europe
4. Set of advocacy materials

Measures of success

1. Publication of survey results
2. Publication of consensus guidelines for quality criteria
3. Implementation of consensus guidelines and development of new CPGL for rare cancers

* Research institutes / patient organisations responsible for project management, funding, surveys, and results analysis. In collaboration with EPAAC WP7 (sarcomas) and RARECARENet (CPGL).

Improve the organisation of health care in rare cancers



Goal 3

Activities

1. 2011/2012: Development of “Horizontal” index measuring access to rare cancer treatment and care in EU 27
2. 2012: Comparative multi-stakeholder case studies (text and multi-media)
3. 2012: Initial Conference (TBD)
4. Rare cancer med. edu. events

Deliverables

1. Access Index and scientific report
2. Series of 3 comparative text and multi-media case studies (2 countries per case study) and related template materials
3. Campaign/advocacy materials for national adaptation
4. Rare cancer events/sessions

Measures of success

1. Participation of all EU 27 Member States
2. Publication of scientific report (Annals of Oncology, Cancer World or else)
3. Availability of at least 3 case studies by end 2012
4. At least 4 events/sessions p.a. (incl. EP/political edu. events)

Improve access of rare cancer patients to new therapies in the EU

www.rarecancers.eu

**→ Sign the Call to Action Against
Rare Cancers**