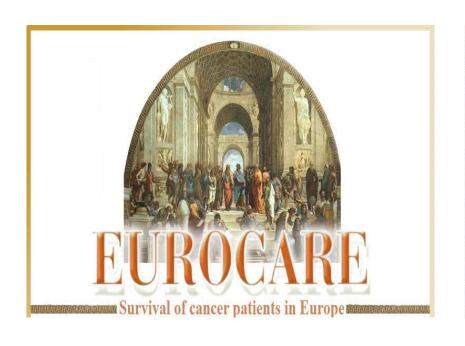
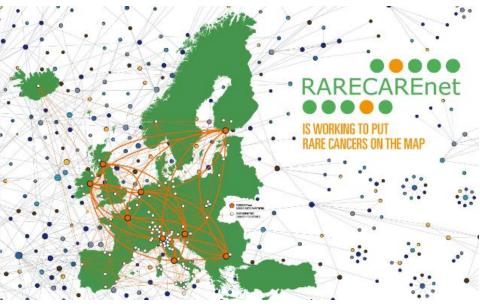
CANCON stakeholder forum - Rome, 15 September 2016 Promoting quality in cancer control: different dimensions, compelling challenges

Organisational perspective

Annalisa Trama

Fondazione IRCCS, Istituto Nazionale dei Tumori, Milan (Italy)



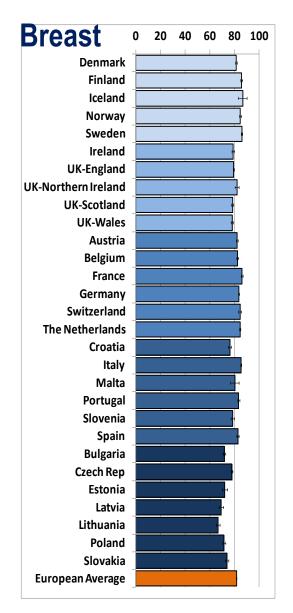


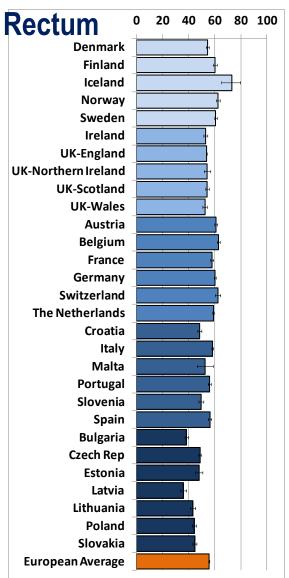
www.eurocare.it

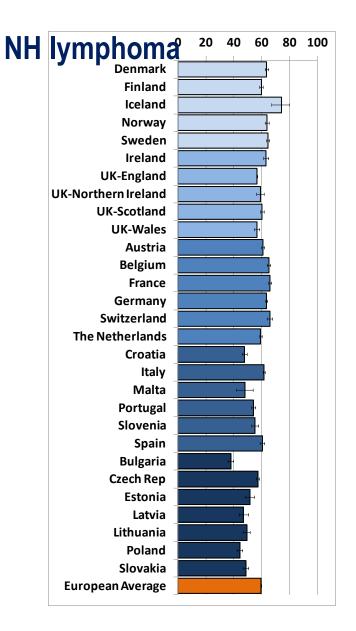
www.rarecarenet.eu

To convince that there is problem

Five-year relative survival 2000-07







Political and professional commitment

Organisational and institutional context

Rare cancers

Incidence (number of new cases)/year < 6/100,000

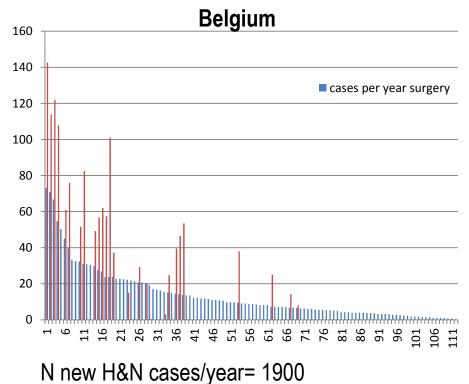
- 1. Head and neck cancers
- 2. Thoracic rare cancers
- 3. Male genital and urogenital rare cancers
- 4. Female genital rare cancers
- 5. Neuroendocrine tumours
- 6. Tumours of the endocrine organs
- 7. Central Nervous System tumours
- Sarcomas
- 9. Digestive rare cancers
- 10. Rare skin cancers and non-cutaneous melanoma
- 11. Haematological rare malignancies
- 12. Pediatric cancers (all)

Fonte: Gatta et al. rare cancers are not so rare: The rare cancer burden in Europe. EJC 2011;47: 2493-2511 www.rarecarenet.eu

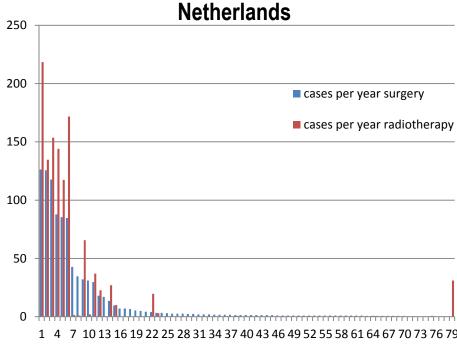
Head & Neck cancers: hospital volume/year (1)

X axis: hospitals

Y axis: N surgeries/year



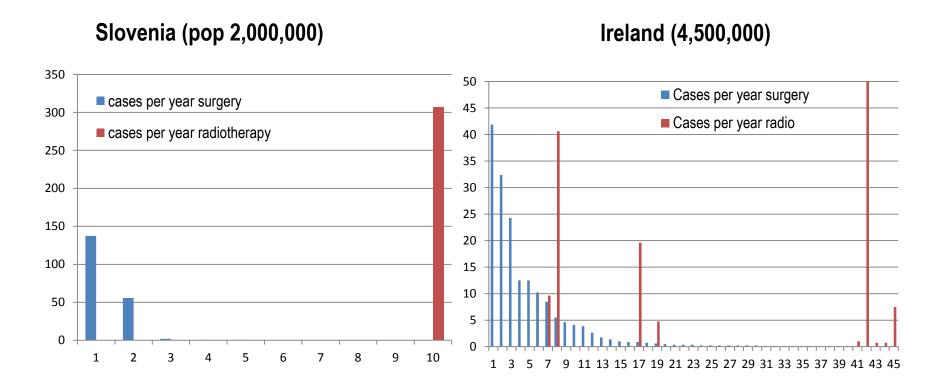
N new H&N cases/year= about 3000



Head & Neck cancers: hospital volume/year (2)

X axis: hospitals

Y axis: N surgeries/year



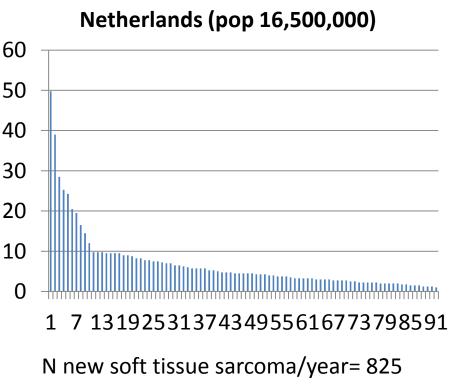
N new H&N cases/year=370

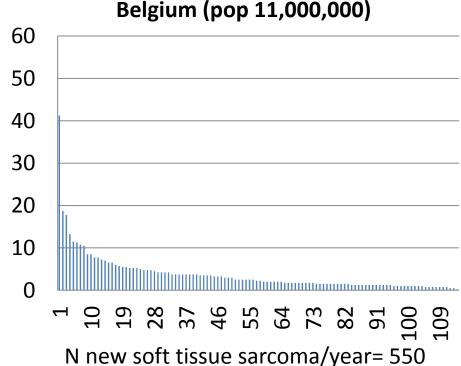
N new H&N cases/year=700

Soft tissue sarcomas: hospital volume/year

X axis: hospitals

Y axis: N surgeries/year





Quality of care

General criteria for Centres of Expertise for rare cancers

- 1. ensure appropriate clinical management according to evidence based guidelines and based on a patient centered multidisciplinary approach
- 2. develop clinical guidelines and good service guidelines
- 3. develop/support **patient pathways** nationally and cross border
- 4. guarantee a learning environment by promotion **of training** and continuing education activities
- 5. foster clinical, translational and epidemiological research
- 6. empower **patients** by providing information adapted to their specific needs, culture and ethnic group (collaboration with patients)
- poses e-health platform to process and share information, biomedical images or clinical samples supported by enough human, structural and equipment resources
- 8. have a transparent quality assurance system including **monitoring and evaluation** of the service provided
- 9. reported **volume** of relevant activities

Integration

- Within the health care system/services
- Health and community services (prevention, rehabilitions, care services)

Flexibility balanced by consolided procedures and methodologies

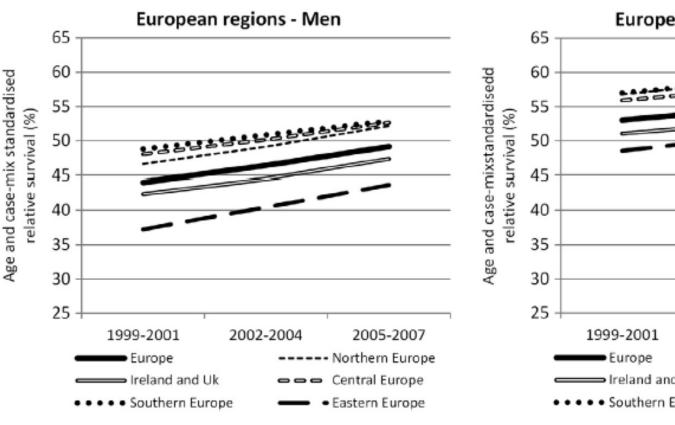
Governance

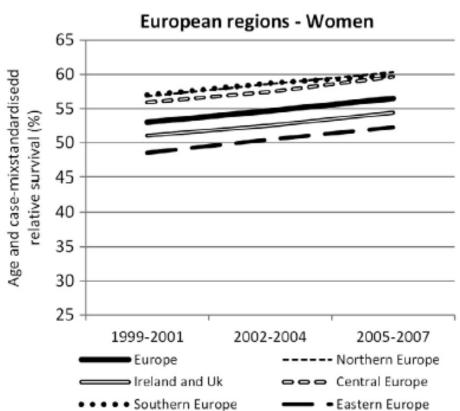
Allignment of professionals and managers

Information system

Evaluation system

Time trend in age and case-mix standardised 5-year relative survival by European region and gender





Source: Baili et al, EJC, 2015

Care after cancer

General criteria for Centres of Expertise for rare cancers

- 1. ensure appropriate **clinical management** according to evidence based guidelines and based on **a patient centered multidisciplinary approach**
- 2. develop clinical guidelines and good service guidelines
- 3. develop/support **patient pathways** nationally and cross border
- 4. guarantee a learning environment by promotion **of training** and continuing education activities
- 5. foster clinical, translational and epidemiological research
- 6. empower **patients** by providing information adapted to their specific needs, culture and ethnic group (collaboration with patients)
- poses e-health platform to process and share information, biomedical images or clinical samples supported by enough human, structural and equipment resources
- 8. have a transparent quality assurance system including **monitoring and evaluation** of the service provided
- 9. reported **volume** of relevant activities

Meaningful engagement of patients

The european perspective



European Commission CONSUMERS, HEALTH, AGRICULTURE AND FOOD EXECUTIVE AGENCY Health Programme

3rd Health Programme

Call: HP-ERN-2016

(European Reference Networks)

Topic: ERN-01-2016

Type of action: HP-FPA

(Framework Partnership Agreement)

Proposal number: 739521

Proposal acronym: EURACAN

Deadline Id: HP-ERN-2016

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ATTACHMENT A - STRATEGIC PLANNING AND GOVERNANCE

- Measure 2.1.3 Mision, Vision, Initial Strategic Plan
- Measure 3.1.1 Network Organogram and Written Statements of Members' Role and Responsibilities
- Measure 3.1.2 Board Terms of Reference
- Measure 9.1.2 Communication Strategy and Plan
- ⊕ Measure 9.1.2 Collaboration Strategy with Affiliated Partners

ATTACHMENT B — PATIENT EMPOWERMENT

- Measure 4.2.1 Sample of information provided to patients and families, i.e. Brochures, Web-site
- Measure 4.2.5 Patient Experience Survey(s) and/or planned activities and timelines to establish a common tool

ATTACHMENT C - ORGANISATION OF CARE

- ⊕ Measure 4.1.1 Patient Pathways and/or Planned Actions and Timelines
- ⊕ Measure 5.1.2 Guides/Recommendations on Multidisciplinary Teams
- Measure 6.3.1 Clinical Guidelines and/or planned activities and timelines for developing Guidelines
- Measure 6.3.2 Policy on the declaration and management of conflict of interest regarding clinical guidelines, patient pathways, and clinical decision making tools
- Measure 6.3.3 Cross Border Pathways and/or planned actions and timelines to develop cross border Pathways

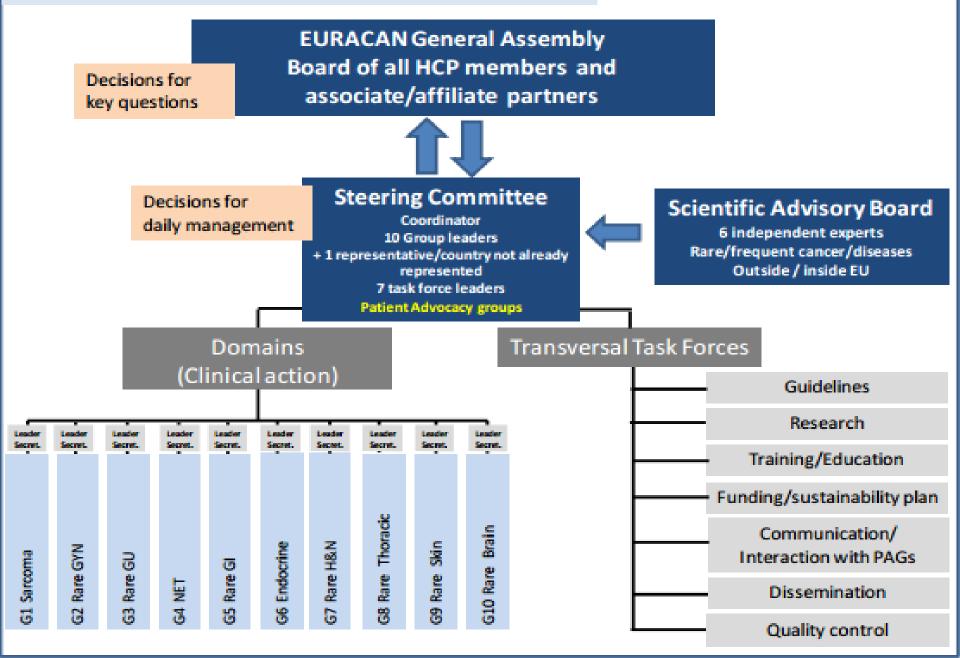
ATTACHMENT D - QUALITY AND INFORMATION SYSTEM

- ⊕ Measure 4.1.4 List of Diagnostic Technologies and Services Certified or Accredited through National, European, and/or International Programs provided by Network Members
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ATTACHMENT E- RESEARCH AND TRAINING

- ⊕ Measure 7.1.2 Strategic Research Plan
- Measure 7.1.3 Annual Report on Research Projects and Clinical Trials and/or planned actions and timelines to develop the Report
- ⊕ Measure 8.1.1 Annual Education Work plan

EURACAN governance





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

EURACAN aims

- i) increase and accelerate access to pathological diagnosis and associated treatments across all EU MS,
- ii) develop dedicated medical training programmes... harmonise the quality of care,
- iii) involve patient advocacy groups ... to enhance overall patients' information and empowerment
- iv) implement "roadmaps" for referral and self-referral of patient to expert centers, to optimize **patients**' care pathways and ultimately quality of care,
- v) develop and continuously review clinical practice guidelines (CPGs) ... **spread and homogenize best practices**,
- vi) carry out a thorough socio-economic assessment of the impact of rare adult solid cancers on patients quality of life and healthcare systems, formulate recommendations to Health Authorities, to lower economic impact of rare diseases on health systems,
- vii) initiate and promote novel translational research programs
- viii) interact with key national international actors/networks and infrastructures involved in cancer care andresearch

Sustainability

Thank you for your attention

