



European
Reference
Networks

***THE IMPORTANCE OF SHARING EXPERTISE AND THE
CHALLENGE TO MANAGE THE EXCHANGE OF KNOWLEDGE
IN HIGHLY SPECIALISED HEALTH CARE:***

*a perspective from the European Partnership Action
Against Cancer (EPAAC)*

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Brussels, June 23, 2014

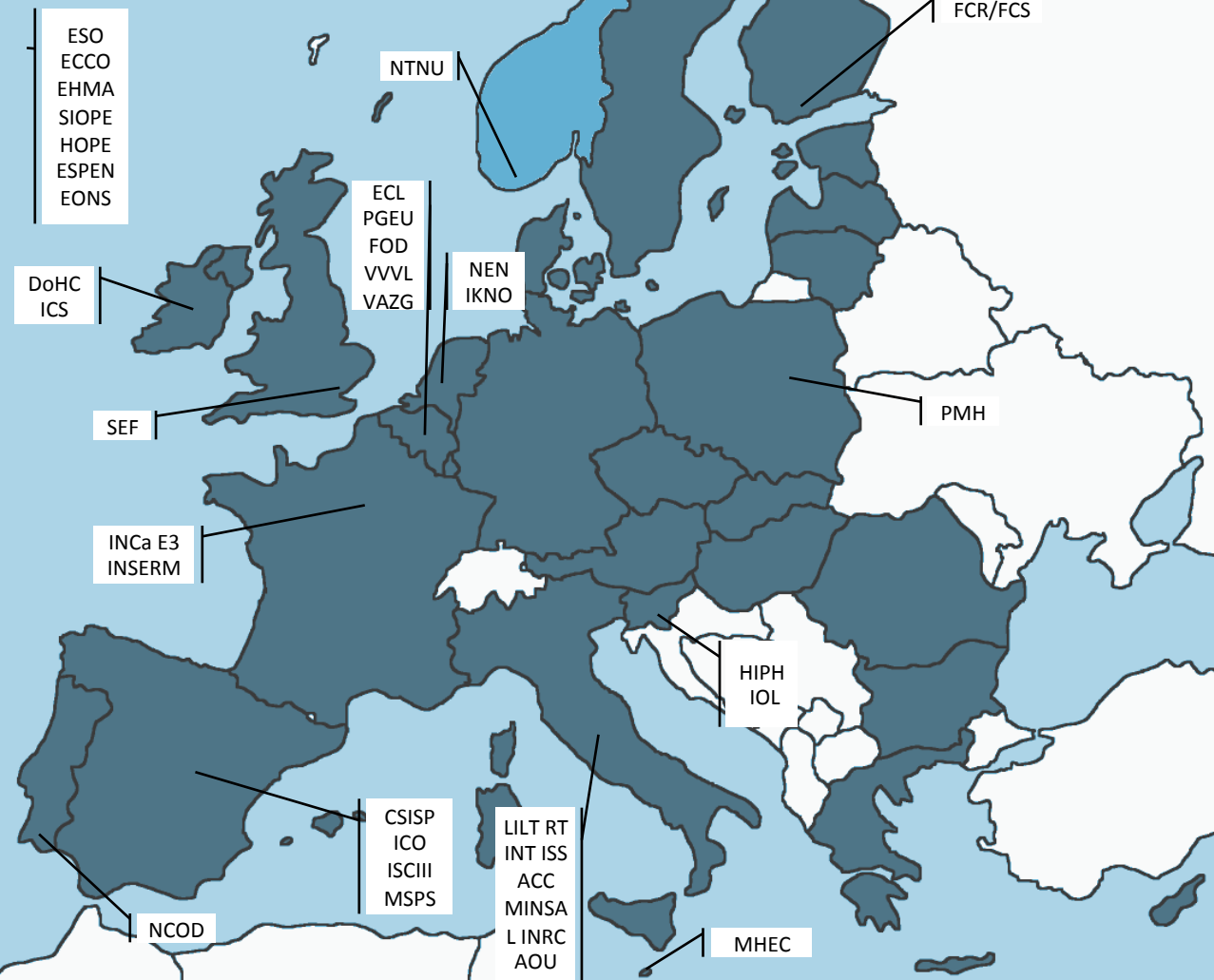
EPAAC

- European Partnership Action Against Cancer
- All relevant stakeholders involved
- Health care WP7: Identify and exchange of best practices
 - Multidisciplinary cancer care
 - Networks in cancer care
 - Feasibility of harmonization of clinical guidelines in rare tumors at EU level
- Time frame: 2011-2013.

EPAAC Partners



INTERNATIONAL:



Project Coordinator:
National Institute of
Public Health, Slovenia

37 associated partners

&

over 90 collaborating
partners from the fields
of oncology and
healthcare

EPAAC perspective

- Cancer treatment has several features that makes planning and organization of health services very relevant to delivering high quality cancer care beyond the individual efficacy of each therapy:
 - *the need to combine different therapeutic strategies,*
 - *spur innovation, and*
 - *uptake of research outcomes into integrated care in the context of a progressive personalization of therapy*

Why do we need to talk about networks and centers of reference?

- Increasing specialization of cancer care
- Fragmentation of cancer care
- Inequality of access to care
- Patient demand for high quality and seamless care
- Debate: More is better?
 - Is expertise associated with a minimum number of cases?
 - Is expertise associated with better results?
 - How to organize the referral of patients?

Why do we need to talk about networks and centers of reference?

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The volume effect in paediatric oncology: a systematic review

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Results: In total, 14 studies were included in this systematic review. Studies with a low risk of bias provide evidence that treatment of children with brain tumours, acute lymphoblastic leukaemia, osteosarcoma, Ewing's sarcoma, or children receiving treatment with allogeneic bone marrow transplantation in higher volume hospitals, specialised hospitals, or by high case volume providers, is related with a better outcome.

Conclusions: This systematic review provides support for the statement that higher volume hospitals, higher case volume providers, and specialised hospitals are related to the better outcome in paediatric oncology. No studies reported a negative effect of a higher volume.

Sarcoma: concordance between initial diagnosis and centralized expert review in a population-based study within three European regions

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Background: Sarcomas represent a heterogeneous group of tumors. Accurate determination of histological diagnosis and prognostic factors is critical for the delineation of treatment strategies. The contribution of second opinion (SO) to improve diagnostic accuracy has been suggested for sarcoma but has never been established in population-based studies.

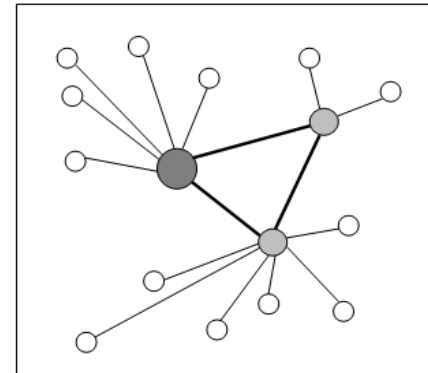
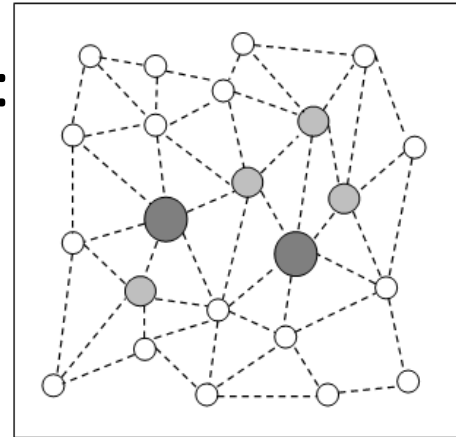
Methods: Histological data of patients diagnosed with sarcoma in Rhone-Alpes (France), Veneto (Italy) and Aquitaine (France) over a 2-year period were collected. Initial diagnoses were systematically compared with SO from regional and national experts.

Conclusion: More than 40% of first histological diagnoses were modified at second reading, possibly resulting in different treatment decisions.

Networks as organizational model that could be a way to respond to these challenges

Defining networks

- Different approaches but similar objectives:
 - Sharing knowledge and/or expertise
 - Concentrating cases: referral of patients
 - Standardizing quality and guidelines
- Critical factors:
 - Clinical information flow
 - Organizational/professional working system
 - Procedures or therapies selected
 - Accountability



Lessons learned in analysing networks in cancer care within the EPAAC project

- A network is a **cluster of professionals** with a variety of levels of integration working with patients with different levels of complexity
- Organization of networks: Some level of **structure and organization is essential** to give stability and continuity to the networks
- **Strong clinical leadership** should be promoted in the network
- **Training of health professionals** should take into account these changes

Lessons learned

- **Strategic cooperation** among institutions in the network may overlap and **coexist with competition**
- Cancer networks could be viewed to some extent as **population accountable systems** based on professionals working at different levels of clinical complexity
- **Evaluation of clinical outcomes:** Experiences in place with linkage to cancer registries although only carried out by a minority of networks

Lessons learned

- No matter how well managed a network may be, **learning and informational mechanisms** should be developed in parallel to actively tackle the multiple **'grey areas'** making up clinical care
- Networks provide a framework for **access to expertise**.
Relevant aspects to take into account:
 - Management of health professionals according to expertise
 - Mechanisms in place for exchange of information on complex patients
 - Promoting cross-cutting learning mechanisms for experts
 - Clinical accountability for the decisions made

WP7 Health Care: To develop, review and harmonize **Clinical Guidelines** (CG) on rare cancers

- Increasing collaboration among different professionals, patient groups and scientific societies at European level
- **Consensus reached on the feasibility of harmonization of European Guidelines for rare tumors.** However, it is necessary to improve methodology, transparency and to manage conflict of interest.
- Guidelines harmonization was seen as prerequisite to the establishment of EU network for rare tumors.
- **Challenge:** the implementation of guidelines and evaluation of outcomes.
- The role of the patient organisations should be strengthened

No networks without effective teamwork!

Networks should work using a Multidisciplinary
approach

Directive 2011/24/EU on the application of patients' rights in cross-border health

Criteria that European Reference Networks must fulfill:

- Have a knowledge and expertise to diagnose, treatment, follow up and manage patients with evidence of good outcomes
- Follow a multidisciplinary approach
- Capacity to produce good practice guidelines
- Contribution to research
- Teaching and training
- Collaborate with other centers of expertise

Multidisciplinary Cancer Care

- **POLICY STATEMENT ON MULTIDISCIPLINARY CANCER CARE**
- **WORKSHOP WITHIN EPAAC WP7**
- This statement has been endorsed by the boards of the following scientific societies: European Cancer Therapeutic Radiology ; Medical Oncology (ESMO) International Society of for Palliative Care (EAPIC) International Psycho-Oncology Coalition (ECPC), European and Europa Donna.

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Policy statement on multidisciplinary cancer care [☆]

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Multidisciplinary Cancer Care

- Optimal clinical decision making associated with MDT
- Working definition of MDT:

Definition Multidisciplinary Teams:

*Multidisciplinary teams (MDTs) are an alliance of all medical and health care professionals **related to a specific tumour disease** whose approach to cancer care is guided by their willingness to agree on **evidence-based clinical decisions** and to co-ordinate the delivery of care at **all stages of the process**, encouraging **patients** in turn to take an active role in their care.*

Core Pillars of MD Care

- MD should cover diagnosis, treatment and survivorship and the way of access to cancer care
- Time of professionals for MDT should be protected
- Designated point of contact for patients
- Databases should record clinically relevant information in order to assess clinical outcomes and benchmarking
- Patient centered approach with available and comprehensible information on clinical and psychosocial
- Policy support from national, regional authorities as well as scientific organizations and patient organizations

CONCLUDING REMARKS

- Stakeholders involvement in relevant cancer care issues is feasible at EU level, as showed in the example of EPAAC.
- Organizational approaches are increasingly relevant in the cancer policy: networks as the best example
- Harmonization of clinical guidelines seems feasible for rare tumors
- Efforts should be focused on implementation of clinical guidelines and assessment of clinical outcomes in networks

Concluding remarks

- Challenges remain:
 - Implementation and compliance
 - Reimbursement
 - External accountability
 - Patient involvement

Questions??

- Thank you!!!

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www.epaac.eu

www.cancercontrol.eu



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