



Ministry
of Health



European Standards of Care for Children with Cancer



Background

- May 2008: on behalf of parent organisations SIOPE led a **report on the status and standards of paediatric cancer units in Europe**
- **Questionnaire on availability of national standards for paediatric oncology/haematology (POH) wards** mailed to representatives of all European countries

Any regulations existing in their countries related to standards for these wards?



European Conference

Warsaw, 14 October 2009

- Partnership between **SIOPE and Communication without Barriers Foundation**
- **Patron**: former EU Commissioner for Health and Consumers, Ms. Androulla Vassiliou
- Supported by the **Polish Ministry of Health**
- First time **multidisciplinary, multiprofessional care team came together** - paediatric oncologists, nurses, pathologists, psychologists, lawyers, survivors, parents, patients, lobbyists, interest groups - **from at least 14 European countries** (EU and non-EU)





Need for childhood cancer standards of care in Europe?

SIOPE Survey says yes

Support for ACTION from all respondents

- To address current **inequalities** and improve the **quality** of paediatric oncology in Europe
- Resulting in minimal **requirements** for paediatric oncology/haematology wards, at least in EU countries
- Outlining **minimal standards** especially for new Member States: supporting implementation of new regulations within limited budgets



European Standards of Care for Children with Cancer

A true *consensus* document

1. Organising **networks of comprehensive care** for children and adolescents with cancer and serious haematological diseases within each country
- 2. National register of childhood cancer**
3. Requirements for **paediatric haematology and/or oncology units**
4. Recommended **staffing levels** for paediatric haematology/oncology wards
5. Continuous **professional development**
6. Components of **care** in a specialist facility
7. Delivery of **therapy**



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8. Monitoring the **late outcomes of cancer**
9. **Psychological and psychosocial care**
10. **Palliative care**
11. The **rights of the hospitalised child**
12. **Social care**
13. **Education**
14. The critical **role of parents**
15. **Rehabilitation**



***How is the
European Partnership for Action against Cancer
helping to improve the quality of care
and outcomes for children and young people with
cancer?***



WP 7: Healthcare

Coordinated by the Spanish Ministry of Health

To identify and assess **best practices across European health services**, promoting the exchange of experiences focusing on innovative organisational approaches, including patient's perspective

Key areas:

- Multidisciplinary care and national/regional networks
- Standardisation of treatment, symptom assessment and follow-up of palliative care
- **Standards of care for children with cancer**



WP 7 Deliverables

*Partnership between SIOPE and
the Polish Ministry of Health*

- Standards of care for children with cancer in Europe – the **document**
- **Survey** report on standards in paediatric oncology units
- **Conference** to increase public and policy awareness of the need to develop standards for care of the children with cancer

Conference

European Standards of Care for Children with Cancer

Warsaw, 20-21 October 2011



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- **Part of EU Presidency held by Poland**
- Led by Polish Ministry of Health
- **Key stakeholder meeting** for European paediatric oncology community, parent organisations and national ministries

Conference



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European Standards of Care for Children with Cancer

Warsaw, 20-21 October 2011

28 countries represented:

- Austria
- Belgium
- Bulgaria
- Czech
- Cyprus
- Estonia
- Finland
- France
- Germany
- Great Britain
- Greece
- Hungary
- Italy
- Latvia
- Lithuania
- Luxemburg
- Malta
- Netherlands
- Poland
- Portugal
- Romania
- Russia
- Serbia & Montenegro
- Slovakia
- Slovenia
- Spain
- Sweden
- Turkey

Conference

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- During **2-day conference**, **22 lectures** grouped into **4 sessions** were presented to almost 70 representatives from 28 countries
- Opened by **Polish Minister of Health, Dr. Ewa Kopacz**
 - child health = priority of the Polish Presidency
 - importance of early diagnosis



Conference

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Warsaw, 20-21 October 2011

Presentations included:

- **National perspectives** on Standards of Care from
 - **Poland, Portugal, Germany, Russia, Romania, Bulgaria**
- **Best practices:** example of international partnerships with specialists in leukaemia
- **Discussion on poor drug development** for children with cancer due to poor commercial interest (all paediatric cancers are rare cancers)

Conference

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Recommendations on implementation of European Standards of Care for Children with Cancer

- **Challenges of EU Clinical Trials Directive** results in difficulty to meet standards – needs to be revised taking into account specificity of paediatric oncology and other rare diseases
- The importance of **continuous professional education**
- **Psycho-social care** not only for patients, but also parents and siblings
- To address inequalities and differences in outcome between countries/ regions, **more twinning/partnering** programmes and knowledge-sharing amongst the different countries should be encouraged



Recommendations on implementation of European Standards of Care for Children with Cancer

- ***Sharing Best Practice:*** aspects such as the proportion of doctors to nurses, access to specialists, nr. of beds. Important: need for better 'early diagnosis'
- ***Professional Partnerships:*** information-exchange, networking and continuous professional training and development
- ***Role of patient/parent advocates:*** excellent partners in advocacy and a major role to improve conditions, but capacity-building needed
- ***Knowledge Exchange:*** several EU initiatives currently taking place => momentum to raise awareness of the needs of children and young people with cancer
- ***Partnership*** between all players (The 'Care Team') needed: paediatric oncologists, patients, parents, nurses, psychologists, counsellors, play therapists and physiotherapists

Next Steps

- **Translation and dissemination of European Standards of Care for Children with Cancer**
 - to ensure equal access to medical services and the best standard of life after illness
 - more translations of the standards are made; more lobbying activities and capacity-building for parent/ patient groups
- **Action to convince authorities to issue national regulations on standards in paediatric oncology**
- **Monitor the process of implementation of recommendations in paediatric oncology centres**

Next Steps

- **Dissemination of European Standards of Care for Children with Cancer**
 - to ensure equal access to medical services and the best standard of life after illness
 - more translations of the standards are made; more lobbying activities and capacity-building for parent/ patient groups
- **Translation:** currently in English, Polish, Portuguese, Spanish, Serbian and Greek
- ***Expected:*** Dutch, Hungarian, Italian...