



Position Paper

# Towards reducing inequalities: European Standards of Care for Children with Cancer<sup>☆</sup>



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## KEYWORDS

Children with cancer  
Standards of care

**Abstract** Despite the increase of cure rates in the treatment of children with cancer there is a significant discrepancy in the outcome within Europe. Data are showing us that there is a difference of 20% in outcomes for young people with cancer when comparing North and Western Europe with Central and Eastern Europe. One of the most important necessities, in order to be able to have comparable results and equitable outcomes about inequalities, is to have the Principle Treatment Centres, meeting a minimum level of standards and being accessible to continuously updated 'best practice'.

The European Society of Paediatric Oncology (SIOPE) has initiated a study in order to monitor the current situation of the European Standards of Paediatric Oncology Centres. The results of the study showed disparities of Standards of Care in the Treatment Centres across Europe. Therefore SIOPE initiated a project aimed at improving the Quality-of-Care of children and adolescents with cancer and to assess the relevant organisational aspects within paediatric oncology.

At the first European Union (EU) Conference in Warsaw 2009, an agreement was obtained from all involved stakeholders to initiate the creation of Pan-European guidelines entitled 'European Standards of Care for Children with Cancer'. The guidelines outlined in this document represent the minimum standards of care that should be implemented at the EU level.

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Describing the different aspects of Care over 15 chapters and available in more than 16 different EU languages these guidelines are used as tools for both professionals and parent/patients groups in order to advocate 'improved standards across EU'.

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## 1. Introduction

Significant progress has been made in the treatment results of children with cancer across Europe. This progress was achieved due to the close collaborations amongst paediatric oncology professionals, within and across the different Member States.

Despite these efforts, disparities in survival rates and significant long-term side-effects in many survivors across Europe are a fact [1,2]. The majority of these disparities are due to the different approach of treatments, the organisation of care and availability of resources across Europe [3–5]. This situation must and should be improved to prevent unnecessary young citizen's suffering and deaths. One of the most important conditions to obtain comparable results and equitable outcomes is that each of the centres delivering the complex treatments required by children and young people with cancer should meet certain minimum standards and provide access to continuously updated 'best practice'. This objective can be achieved only if each centre takes an active part in research or in a network that provides access to 'State of the Art' treatments. To address these inequalities, the European Society of Paediatric Oncology (SIOPE) has carried out a joint study in order to investigate the current situation and the Standards of Paediatric Oncology Centres across Europe, in partnership with ICCPO, the International Confederation of Childhood Cancer Parent Organisations [6].

Based on the results obtained from this study, which highlighted the disparities in the Standards of Care in Treatment Centres in Europe, SIOPE initiated a project in order to improve the Quality-of-Care of children and adolescents with cancer as well as to assess the relevant organisational aspects in paediatric oncology.

At the first European Union (EU) Conference on 'European Standards of Care in Childhood Cancer' in Warsaw 2009, an agreement was obtained from all involved stakeholders to initiate the creation of 'Pan-European Paediatric Oncology' guidelines. This initiative has led to the current existing guidelines entitled 'European Standards of Care for Children with Cancer'. The Guidelines represent the minimum standards of care that should be provided. They consist of a genuine 'consensus document' agreed by all stakeholders (multidisciplinary professionals, patients and their families). These European Guidelines aim to address the current inequalities existing in the Standards of Care. The guidelines were initially targeted at the EU Member States but are not confined to these countries.

These standards include both the infrastructure for diagnosis and treatment as well as common work practices and training for health professionals, including participation in clinical trials.

Significant progress has been made since the Warsaw Conference in 2009 which launched this project and partnership between paediatric oncologists, patients, parents, nurses, psychologists, counsellors, play therapists and physiotherapists.

The implementation of the Standards at national level, possibly through national cancer plans, would be a vital 'next step', improving the Quality-of-Care for children with cancer, increasing survival rates and enhancing the Quality-of-Life for childhood cancer survivors. Applying harmonised Standards of Care would guarantee more accurate diagnosis and risk stratification and application of 'state-of-the-art' treatments and follow-up practices, particularly important for young patients with life-threatening diseases like cancer who receive intensive treatments at an early stage in their life [5].

Such initiatives require adequate political and financial support.

Through the EU-funded 'European Partnership for Action against Cancer' (EPAAC) initiative, the Polish Ministry of Health and SIOPE joined forces to disseminate the Standards that were finalised, during the second Warsaw Conference in 2011, by a team of multidisciplinary, multi-professional 'team of care' experts [7]. Fifteen representatives from national ministries in Europe, actively participated in the discussions with paediatric oncology professionals and parent representatives, addressing the Standards of Care. In conclusion the discussions highlighted the fact that different Member States are facing significant disparities in the availability of services and the quality-level of services provided to children with cancer. There is still a long way to go but improvements are being made. As part of EPAAC, SIOPE plans to launch in 2013 a new Europe-wide survey in order to evaluate the implementation of these Standards and to assess the current national situation, providing a comprehensive country-by-country analysis of the state-of-play.

The proposed described guidelines are directed to all those who are responsible for health issues across Europe: Doctors, nurses working within paediatric oncology units, parent organisations, politicians as well as all those willing to work with health personnel to optimise cancer care.

Clearly, each country has its own healthcare system and this will determine the availability of funds as well

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