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Position Paper

European Survey on Standards of Care in paediatric oncology centres[☆],[☆☆]

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Abstract ***Background:*** In recent years, the European Commission has supported an increased focus on rare cancers in order to improve quality of care, disseminate best practice and set up networks to improve access that is essential to continued progress. At European Union (EU) conference in 2009, an agreement was reached to create a 'European Standard of Care for Children with Cancer'. In 2013, the European Paediatric Oncology Society launched a Europe-wide survey in order to assess the implementation of the Standards.
Methods: Representative experts from 36 countries, including 27 EU members, were invited to complete a questionnaire describing the quality of treatment and care received by young

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cancer patients in their country, together with the characteristics of the health care infrastructure and paediatric haematology–oncology (PHO) teams.

Findings: Thirty-five European countries provided comprehensive responses. Within the responding countries, 341 PHO centres were identified. Only 18 countries consider they have full diagnostic services, all necessary drugs and supportive care. The annual incidence rate is approximately 146.1 new cancer cases/million children and adolescents. In 24 countries, paediatric haematology and oncology is officially recognised as a specific qualification. A total of 1178 specialists certified in PHO are currently working in Europe. Finally, 31 (88.6%) countries provide a multidisciplinary palliative care for terminally ill children.

Interpretation: This survey provides quantitative data that demonstrate the current healthcare inequalities for children and adolescents with cancer in Europe. This variability in care provision and quality is likely to underlie the variation in childhood cancer survival rate in these countries.

1. Introduction

Childhood cancer remains a significant public health issue, even if it can be regarded as a rare disease and despite an overall high survival rate as compared to adult cancers. It remains the leading cause of death from disease in childhood beyond infancy. Only international collaboration between the European paediatric haematology–oncology (PHO) community of health professionals, researchers, parents, patients and survivors together with all stakeholders will give a chance to overcome the challenges to increase both cure and quality of cure of children and adolescents with cancer and to warrant long-term sustainability. Increasing complexity of diagnosis, risk stratification and treatment planning and delivery requires experienced multidisciplinary input that is hard to bring together or maintain for rare diseases and where national populations are small. There is an urgent need for quality-assured clinical networks in European paediatric oncology that support care, research and training, in order to make progress in rare diseases. This is being approached through partnership working between health care professionals and representatives of the affected patient groups [1].

All centres delivering the complex treatments and follow-up required by young people with cancer should meet certain minimum standards and provide access to continuously updated ‘best practices’. This is one of the most important conditions to obtain equitable outcomes in childhood cancer, and it can be only achieved if each centre actively takes part in research networks providing access to state-of-the-art treatments.

However, several studies have highlighted the existing disparities in treatment results in different European countries. The latest results from European Cancer Registry (EUROCARE) 5, a cancer registry-based project on survival of cancer patients in Europe, showed no improvement in survival of children with tumours that have the worst prognosis [2]. Moreover, across Europe, there are still unacceptable disparities in overall survival of children and adolescents with cancer [3]. One of the main findings from this study is that survival is 10–20% lower in Eastern Europe than in Western Europe. Disparities increase for cancers with poor outcomes (acute myelocytic leukaemia (AML), ependymoma, osteosarcomas, Ewing sarcoma and rhabdomyosarcomas).

This article describes the essential work led by the European Society for Paediatric Oncology (SIOPE), the pan-European childhood cancer organisation that has a long history of working with the parent/patient community, supported by European Union (EU) initiatives (European Partnership on Action Against Cancer [EPAAC], The European Network for Cancer research in Children and Adolescents) to establish the baseline provision, access, and variation as a starting point to move forward.

In order to address these inequalities, SIOPE initiated a project to improve the quality of care of children and adolescents with cancer, as well as to assess the relevant organisational aspects necessary to continue to strengthen the research network and capabilities in paediatric oncology.

At the first EU Conference on the ‘European Standards of Care in Childhood Cancer’ held in Warsaw in 2009, all involved stakeholders agreed to initiate the creation of ‘Pan-European Paediatric Oncology’ guidelines. This initiative led to the existing ‘European Standards of Care for Children with Cancer’ published online in www.siope.eu, a set of guidelines with the minimum requirements that should be met in every childhood cancer treatment centre (related to infrastructures for diagnosis and treatment, training for health professionals and work practices) [4–6]. The scope of the Standards is not limited to single European countries as they encourage participation in clinical trials, which usually involve international collaboration by necessity as individual childhood cancer types are rare. Through the EU-funded ‘EPAAC’ initiative, the Polish Ministry of Health and SIOPE joined forces to disseminate the Standards as