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
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 care 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
finalised by a team of multidisciplinary, multi-professional experts. During the Second Warsaw Conference in 2011, 15 representatives from European national ministries, paediatric oncology professionals and parent representatives actively discussed and pointed out the significant disparities in the availability and quality of the services provided to children with cancer in different EU member states [5]. Some small improvements were noticed as compared to the 2009 situation and, in order to further facilitate the process, the Standards were translated in more than 16 different European languages (they are currently available on the SIOPE Web site: http://www.siope.eu/european-research-and-standards/standards-of-care-in-paediatric-oncology/) [7]. Five years later, the full implementation of the Standards at the national level would represent a vital step forward to improve the quality-of-care of children with cancer, increase survival rates and enhance the quality of life of childhood cancer survivors and access to trials and innovation. The harmonisation of these Standards across Europe would guarantee more accurate diagnosis, a better risk stratification and an enhanced application of state-of-the-art treatments and follow-up practices, all fundamental aspects for young patients with life-threatening diseases like cancer, who receive intensive treatments at an early stage in their life [8,9].

2. Objectives

To evaluate the implementation process of the ‘European Standards of Care for Children with Cancer’ in all paediatric oncology centres and to assess and review the current situation as concerns the quality of care of children and adolescents with cancer across Europe.

3. Methodology

Within EPAAC Work Package 7, SIOPE has launched in 2013 a new Europe-wide survey to assess the implementation of the Standards of Care for Children with Cancer, as well as to assess the current national situation. A questionnaire was designed addressing the main topics of patient and health professional demographics, how care is organised and the availability of complex treatments and supportive care. This country-by-country analysis provides essential information to understand the current health inequalities between different European countries. The information and data were provided by at least one senior health professional leader per country, who summarised the existing situation in his/her country. We contacted all Chairs of Europe’s National Paediatric Haemato-Oncology Societies (NaPHOS) and experts from 36 European countries, who provided comprehensive responses to the survey on the ‘European Standards of Care for Children with Cancer’.

4. Results

4.1. Demographics

We obtained answers from 35 NaPHOS out of 36 (97.2% response rate) of those polled (Appendix A1). All data in this chapter are based on figures provided by the Chairs of European NaPHOS and, hence, assumed to be based on actual data or official estimations. The age limit for a patient to be admitted to a PHO unit is 17–18 years in 23 countries (65.7% of the total), 16 years in ten countries (28.6%), while in five of them the decision as to where to set the age limit depends on each treating centre. In Denmark and Spain, PHO centres only admit patients below the age of 15 years.

In the countries that responded to the questionnaire, there is a population of approximately 137,228,778 children and adolescents (under 18 years). For the age range 0–14 years, that is used internationally for childhood cancer registration, the estimated population is 108,681,569 children.

According to data derived from the questionnaire, the annual number of children and adolescents below 18 years diagnosed with cancer in Europe is approximately 20,045, with approximately 11,347 cases below 15 years. The annual incidence calculated from the survey data is approximately 146.1 cases per 1 million of children and adolescents. Significant differences in incidence rates are observed between some countries, from 103 to more than 230 cases/million. The incidence in most countries presented is in the range of 140–160 new cases/million children and adolescents (Table A1). These differences are generally in line with those reported by the population-based cancer registries [3].

4.2. How care is structured

Within the reviewed countries, a total of 341 centres were reported as reference or principal PHO centres. According to responders, more than half of the countries, 18 (51.4%), have full diagnostic services, necessary drugs and supportive care in all their PHO centres. In three countries, only a few centres fulfil these essential requirements (the requirements for principal paediatric oncology centre are presented in Table A2).

In addition, a number of centres were reported in some countries as a satellite: this means that specialised centres that are responsible for accurate diagnosis, risk stratification, and complex treatments liaise with designated shared-care local hospitals that provide less complex components of supportive care, monitoring and simple chemotherapy closer to most patients’ homes [10].

The existing number and location of specialised centres for paediatric oncology is sufficient to diagnose and treat all children with cancer in all countries. We should
be aware, however, that the total national populations aged <18 years in European countries vary from approximately 80,000 (Iceland, Malta) to 20 million (Turkey) and the number of reported centres do not always correlate closely with population size. The number of newly diagnosed patients in every specialised centre widely varies depending on the country, with the lowest rates in Iceland and Malta (12 diagnoses/centre) versus the highest rate in Ireland, which has a single national centre (170 diagnoses/centre). Patients from Malta are referred to the United Kingdom for some very specialised treatments, while in Latvia and Iceland patients, who need bone marrow transplantation, specialised radiotherapy or surgery are in general referred to foreign centres. The estimated overall average for Europe is 53.5 diagnosed patients/centre.

4.3. Organisation of care at the national level

For the majority of responding NaPHOS (51.4%), distances from patient’s home to paediatric oncology centre are sometimes too long, and they are mostly too long for 37.1% of the responders. Patients in Former Yugoslav Republic of Macedonia always have to travel excessive distances to receive specialised treatment in PHO centres. Some countries have established a system of ‘shared care’ in order to facilitate access to some aspects of care closer to home, in collaboration with the principal treatment centre. This is the model of ‘hub’ and ‘spoke’ [11]. Such systems are more or less frequently available in most countries (26 countries, 76.5% of the total). However, in eight countries, this system is not available.

In 29 countries (82.9%), a universal population-based childhood cancer registry is provided. Nevertheless, nine registries do not use the International Classification of Childhood Cancer for recording data on cancer in children. It should be also noted that in six countries, such a registry does not exist or is not yet known to the treatment centres.

4.4. Type of care

Interesting information also came from the answers to whether centres in each country are able to deliver outpatient care, home care or residential facilities (‘home from home’) to support parents and other family members. It seems that outpatient care is not available in Bosnia–Herzegovina and rarely available in Belarus and Ukraine. On the other hand, residential facilities are available in Czech Republic, Serbia and Slovenia, while it is mostly available in the majority of countries. In nine countries, this facility is not available.

In 29 (82.9%) European countries, an established national childhood cancer research society or network exists and recommends the optimum treatment protocol for each type of cancer. In six countries, however, such organisation did not exist at the time of the survey (Belarus, Estonia, Latvia, Portugal, Serbia, and Ukraine). In the majority of countries (65.7%), the costs connected to the implementation of treatment in accordance with the recommended therapeutic programme are refunded by the state or by insurance institutions (28.6%). However, in some countries, expenses are partially covered by the state and insurance societies. The costs of drugs considered ‘off-label’ are also refunded in 28 (80.0%) countries, except Bosnia–Herzegovina, Bulgaria, Estonia, Greece, Latvia, Romania, and Serbia.

Appropriate long-term monitoring of outcomes is provided as a standard in the majority of countries. The rights of patients and their parents to be fully informed on cancer diagnosis and treatment are respected in 77.1% of the responding countries. In the other countries, the aforementioned rights are perceived as mostly guaranteed.

Almost all respondents (94.3%) stated that children with cancer and their families have been offered psychological support before, during and after the treatment. Psychological support in Denmark is only available during treatment, while PHO units in Belarus and Ukraine rarely offer psychological support to sick children and their parents.

Oncologists in 27 (77.2%) countries have the possibility to provide terminally ill children with comprehensive palliative care through a multidisciplinary team. In four countries, this possibility rarely occurs and in four countries (11.4%) comprehensive palliative care is not available. In 51.4% of the countries, palliative care is provided in each paediatric centre, and it accounts for 289 units. In four countries, additional palliative care is provided by local hospitals and in other five countries separate paediatric hospice services are available.

Only four (11.4%) countries guarantee post-treatment support to help patients reintegrate back into education and society. In 14 (40.0%) countries, such services are guaranteed in most cases.

4.5. Availability

In 65.7% of the countries, all PHO centres are generally equipped with the necessary facilities to accurately and efficiently diagnose childhood and adolescent cancers. Most units dispose of the necessary facilities in 31.4% of the countries, while in the Ukraine only a few centres.

None of the centres in Serbia can offer a single or two-bedded room equipped with all necessary facilities, while only some centres in Belarus, Bosnia–Herzegovina, Romania and Ukraine can provide such services.

Playground and education areas for children are available in a few centres in Bosnia–Herzegovina, Finland and Ukraine. Parents of children with cancer
treated in Serbian centres do not have access to kitchen and bathroom facilities and in six additional countries only a few centres can offer such facilities. While education and play facilities for children are accessible in 32 (91.4%) countries, this is rarely available in three countries. An age-appropriate environment is created in 26 (74.3%) countries, but in Serbia this is not the case. The right to appropriate information is considered in all countries as well the right to privacy and a human right.

In 26 (74.3%) countries, a separate day ward area is provided as standard, while in nine countries it is not. In most of the European countries, the specialised centres have intensive care and high dependency units, units that have the potential to ventilate and carry out haemodialysis and leukapheresis without the requirement to transfer the child to a different hospital. However, in five countries, not all PHO centres have direct access to such services.

The availability at all times of several important services for paediatric oncology units is presented in Fig. A1. These services include paediatric surgery, neurosurgery, radiotherapy, 24/7 access to diagnostic imaging, appropriate laboratory investigations to cover emergency admissions, cytotoxic therapy and supportive medicine, facilities for the preparation of cytostatics, availability of blood products (especially blood, platelets, and commonly used protein fractions). In Ukraine, 24/7 diagnostic imaging as well as the preparation of cytostatic are not available.

4.6. Multidisciplinary teams and delivery of care

Staffing levels required in every PHO unit are not officially regulated in almost half of the countries (16 countries, 45.7% of the total). Interestingly in four countries, psychology services are not available as a standard. Education teachers are not available within the ward in seven countries (Fig. A2). Multidisciplinary team meetings to discuss individual patient’s treatment plans are regularly organised in all countries except Ukraine. In two countries, it is not mandatory for all members of the staff to undergo continuous professional development and training.

In most countries (24 countries, 68.6% of the total), paediatric haematology and oncology are officially recognised as a specific qualification. This specialisation is not recognised in ten (28.6%) countries: Belarus, Estonia, Finland, Greece, Ireland, Malta, Norway, Serbia, Slovenia, and Spain. According to the respondents, a total of 1178 specialists certified in PHO are currently working in Europe. Although their representatives confirmed that this qualification exists, Italy and Lithuania did not provide this information.

On average, every specialist takes care of more than 19 patients annually diagnosed in each country (the value ranges from 4 to 35).

4.7. Parents and patients

Answers related to the rights of every hospitalised child and adolescent in the ward varied enormously across Europe.

The possibility for parents to be constantly involved in the treatment is considered as a right in all European countries. Adequate accommodation for parents within the hospital premises is guaranteed in 30 (82.9%) countries, but rarely in 5 countries, while there is no accommodation available in Serbia.

Almost all respondents stated that the access to rehabilitation services during/after the treatment is not a major problem in their countries. In six countries, there are a few possibilities to access rehabilitation services after the treatment, while in Ukraine the current needs for such services exceed the available resources.

In the majority of countries (80%), support systems are in place to help patients and their families to deal with social, administrative, financial and legal issues. Such support systems are not established in seven countries. In Estonia hospitals, regional social workers are involved in helping patient’s families on the aforementioned issues.

5. Discussion and conclusions

SIOPE has carried out this survey jointly with the national organisations of professionals responsible for delivering childhood cancer care in Europe, in order to establish the current attainment of the European Standards of Care for Children with Cancer by the existing paediatric oncology centres across Europe and to provide a comprehensive description of the situation in each country.

The incidence rates of childhood cancer in most countries presented are in the range of 140–160 new cases/million children and adolescents, nevertheless significant differences in incidence are observed between some countries. These differences are generally in line with those reported by the population-based cancer registries [3]. We should be also aware that the total national populations aged <18 years in European countries vary from approximately 80,000 (Iceland, Malta) to 20 million (Turkey) and the number of reported centres do not always correlate closely with population size. It results in the number of newly diagnosed patients in every specialised centre and widely varies depending on the country. The estimated overall average for Europe is 53.5 diagnosed patients/centre, and according to European Standards of Care for Children with Cancer, more than 30 diagnosed patients a year is sufficient to ensure the experience of a staff working in the centre [7].

All children with cancer should be treated according to the best available treatment protocols. There is general agreement that this is best provided within units that are active in clinical research and cancer
registration processes. When available, children should be offered the opportunity to participate in relevant clinical trials that aim to improve the optimal treatment for all children. Where there is uncertainty about the optimal treatment, these trials may be randomised [12–14]. In 29 of European countries, an established national childhood cancer research society or network exists and recommends the optimum treatment protocol for each type of cancer. In six countries, however, such organisation did not exist at the time of the survey. It can be one of major causes of disparities in survival rates in childhood cancer observed across Europe and it is a big challenge for paediatric oncology community to improve access to modern therapies.

Each PHO centre requires a number of standard facilities to cater for patients and their families as well as approved clinical protocols and link-ups with other specialised units should there be a need for further consultation and/or to offer some procedures (‘shared care’) to patients living close by.

In 23 countries, all PHO centres are generally equipped with the necessary facilities to accurately and efficiently diagnose childhood and adolescent cancers. Most units dispose of the necessary facilities in 11 countries, while in the Ukraine only a few centres. None of the centres in Serbia can offer a single or two-bedded room equipped with all necessary facilities, while only some centres in Belarus, Bosnia–Herzegovina, Romania, and Ukraine can provide such services. One can assume that patients treated in centres which do not fulfil standards for facilities may be less privileged as infections are concerned and it can result in treatment failures more frequently. Key components of a PHO unit include inpatient, day ward and outpatient facilities, as well as residential facilities for parents and siblings. In addition to this, time spent at home for the patient should include the support of local social services. It seems from the questionnaire results that outpatient care is not available in Bosnia–Herzegovina and rarely available in Belarus and Ukraine. On the other hand, residential facilities are not available in nine countries.

All children in hospital should have the right not only to education but also to enjoy recreational activities appropriate for their age. These are essential to maintain a degree of normality and to continue the child’s social and educational development throughout their cancer pathway. Within a ward, there must be one room dedicated to education and a separate room available for relaxation and play. The parents should be able to be with the child at all times. The ward should contain appropriate facilities: kitchen, bathroom for parents and sleeping accommodation on or very close to the ward.

Playground and education areas for children are not available in all centres localised in three countries. Parents of children with cancer treated in Serbian centres do not have access to kitchen and bathroom facilities and in six additional countries only a few centres can offer such facilities. While education and play facilities for children are accessible in 32 countries, this is still rarely available in three countries. An age-appropriate environment is created in 26 countries.

It is essential that a principal treatment centre has access to an intensive care and high dependency unit. In most of the European countries, the specialised centres have intensive care and high dependency units, units that have the potential to ventilate, carry out haemodialysis and leukapheresis without the requirement to transfer the child to a different hospital. However, in five countries, not all PHO centres have direct access to such services. It makes difficult or impossible to treat critically ill children with complications resulted from intensive chemotherapy.

For the majority of responding NaPHOS, distances from patient’s home to paediatric oncology centre are sometimes too long. However, we should mention that in some cases travelling long distances to have access to highly expert, unique surgical treatment, radiotherapy or access to new drugs is also acceptable.

The results of this survey demonstrate the many and varied issues faced by the paediatric oncology community and highlight the existing healthcare inequalities in Europe. Whilst each country has its own healthcare system, and it is the responsibility of the state to determine the availability of funds as well as the social structures and conditions under which childhood cancer treatment and care should be developed, SIOPE advocates for uniform recognition of the needs of children with cancer wherever they live in Europe.

The ambition, indeed expectation, should be that every European country includes specific reference to the requirements and expected standards for age-appropriate treatment and care for children and adolescents with cancer in its National Cancer Control Plan.

As outlined in this document, a consensus strategy is urgently needed and should be implemented in each country. This would allow improvement in quality of care, more uniform standards and more efficient use of available resources, thereby ensuring more equitable access to effective treatment and care for all patients. The creation and sustainability of high-quality multidisciplinary clinical teams to treat children and young people with cancer requires the provision of postgraduate training, consistent, continuous professional development for all staff concerned and knowledge of the burden of cancers in this age group and their outcomes on a national basis.

The data collected from this survey will be used to raise awareness on the existing disparities and important issues encountered by the European paediatric oncology centres and wards. These data will also be used to tackle inequalities across Europe by addressing all relevant EU and national decision makers. Since the time of the survey, several countries have made progress in forming national PHO organisations (Portugal) or, for smaller countries (e.g. Baltic States), an alliance between...
neighbouring countries enables to improve their efficacy in diagnostics and treatment childhood cancer. For the first time, comparative analysis of timely facts and figures provided by national childhood cancer professionals is available to illuminate current healthcare inequalities existing across Europe. The reduced availability and quality of care in Eastern European centres can be linked to the lower average childhood cancer survival rate in these countries.

Conflict of interest statement

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.ejca.2016.03.073.

Table A1

<table>
<thead>
<tr>
<th>Country</th>
<th>Age 0–18 years</th>
<th>Population</th>
<th>Annual no. of diagnosis</th>
<th>Incidence/ million</th>
<th>Age 0–18 years</th>
<th>Population</th>
<th>Annual no. of diagnosis</th>
<th>Incidence/ million</th>
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<td>1,427,378</td>
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<td></td>
<td>570,000</td>
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<td>975,272</td>
<td>66</td>
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<td>400–450</td>
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<td>1600</td>
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<td>20,045</td>
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a Lack of data.

b Incomplete data.
Fig. A1. Services available for PHO centres.

Fig. A2. Staffing levels in respect to Standards.
References


