European Standards of *Care*

For Children and Adolescents with Cancer

2025

Childhood Cancer International EUROPE

SIOP Europe
the European Society for Paediatric Oncology

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About

Childhood Cancer International – Europe

Childhood Cancer International – Europe (CCI-E, or CCI Europe) represents childhood cancer parent and survivor groups as well as other childhood cancer organisations in Europe: more than 63 organisations in 34 European countries are members of CCI-E. CCI Europe works together with all relevant stakeholders for the same goal: to help everyone affected by childhood cancer thrive, free from lasting impact.
www.ccieurope.eu – office@ccieurope.eu

European Society for Paediatric Oncology (SIOPE)

The European Society for Paediatric Oncology (SIOPE, or SIOP Europe) is the single united European organisation representing all professionals working in the field of childhood cancers. With more than 2,700 members across 36 countries, SIOP Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe.
www.siope.eu – office@siope.eu

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10. Cross-border Care and Research

Key messages

- Every child and adolescent with cancer has equal right to access state-of-the-art treatment and care.
- Collaboration and cross-border care is crucial in the treatment of children and adolescents with cancer, as not all treatment modalities can and need to be available in every European country, but every child must have access to all modalities.
- International initiatives, such as ERNPaedCan, can drive international collaboration forward.

10.1 Why cross-border care?

International collaboration in the care of children and adolescents with cancer has been a cornerstone in the ongoing development and improvement in paediatric oncology. As all types of cancer in children and adolescents are rare, cooperation across country borders has been crucial for gaining experience and pooling enough similar patients to study effects and outcomes of treatment.

Examples of the international collaboration include:
1) Developing treatment protocols (e.g., AIEOP-BFM protocols for acute lymphoblastic leukaemia, PNET 5 trial for medulloblastoma, INFORM registry to answer biological questions).
2) Researching new treatment modalities, medicines, and their outcomes (including acute toxicities and late effects).
3) Educating HCPs.
4) Providing advanced diagnostics.
5) Evaluating complex patients in expert tumour boards.
6) Providing highly specialised care (e.g., proton irradiation, CAR-T, experimental therapy).
7) Researching and collaborating on long-term follow-up care.

Every European country has a different way on how healthcare is organised and delivered. Regardless of the steady development in healthcare systems, there are major differences in access to diagnostic possibilities and treatment for children with cancer (93). As a result, disparities in survival rates exist among cancer units and among European countries, with up to 20% worse outcomes in Eastern Europe (94). Differences can be influenced by the countries' economic status, geography, number of citizens, and treatment funding (94, 95). Nevertheless, all children and adolescents with cancer should have access to fast diagnosis and the best care available.

To diagnose and treat rare diseases, including childhood cancer and especially the different subtypes, specific infrastructure is needed. Due to the low patient numbers, it is not realistic that every step of the path from diagnosis and treatment could and should be provided in every European country (e.g., proton

therapy). Not only the infrastructure and machines need to be available but also trained personnel. Therefore, performing diagnostic steps or treatment abroad can be more economical than providing the care in their own country. Therefore, structuring an impactful and well-functioning international network is pivotal → SEE CHAPTER 8.2.

10.2 European Reference Network on Paediatric Cancer (ERN PaedCan)

European Reference Networks (ERNs) are a European Union initiative that intends to promote cooperation among national healthcare systems. The vision of ERN PaedCan is to reduce inequalities in childhood cancer survival by providing high-quality, accessible, and cost-effective cross-border healthcare, regardless of where in Europe the children and adolescents live. ERN PaedCan aims to bring together specialists across Europe and to facilitate exchange of expertise and knowledge. Some of the prioritised aims include holding virtual tumour boards where medical expertise and knowledge are exchanged rather than patients having to travel, providing guideline documents to HCPs, performing reference diagnostics (e.g., molecular risk grouping, pathology, and imaging), and providing patients access to highly specialised interventions (e.g., complex surgery, proton therapy, and transplantations).

ERN PaedCan aims to bring together specialists across Europe and to facilitate exchange of expertise and knowledge.

Member states can apply to the ERN PaedCan for funding to offer cross-border and highly specialised care to patients (www.paedcan.ern-net.eu).

10.3 Treatment processes and challenges

Travel decisions in medicine need clinical networks and referral pathways, which may include relationships between clinical centres when services are unavailable in a country (96). Although treatment abroad is offered as a possibility by local clinicians, patients or parents may choose not to travel. Cultural conditions, including language and the ability to communicate complex medical issues, are highlighted as a key concern during treatment. These aspects can be a barrier for treatment abroad. Continuity of care and sharing medical information are challenges during treatment. These key aspects must be considered during cross-border care, and a specific and detailed preparation plan between the clinics (clinic in home country and clinic abroad) is of utmost importance. In addition, the complexity of patients returning home after unsuccessful treatment abroad is another challenge. Parenting during oncological treatment abroad can be another challenge.

One motivation for patients and parents to travel abroad includes second opinions on diagnosis and treatment (97). Access to treatments unavailable in the home country is another reason. These treatment modalities are either not approved despite being routinely available in other countries or they are experimental or early phase clinical trials.

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Three travel possibilities can be identified:

1) individual travellers to treatment centres, drawing upon knowledge of acquaintances, family, and friends;
2) patients formally referred by their treating clinician and healthcare system (for both standard treatments and emerging technologies);
3) those who receive services abroad, typically screening, but for whom treatment is a less primary rationale for travel (97).

Importantly, cross-border care does not always imply that the patient travels abroad. Shipping tumour material for reference examination or having tests not available in the home country performed (e.g., molecular testing, drug testing) are also included in cross-border care. Participation in international tumour boards is part of cross-border care.

10.4 Patient safety, risk and outcomes

Given the time sensitivity of cancer treatment, avoiding local treatment while waiting for travel approval and regulations to continue treatment abroad is a challenge. Treatment disruptions due to travelling, delays during treatment abroad, but also the benefits to the new clinical situation can affect the outcomes negatively or positively. For some countries and centres, it is a challenge to establish long-term or short-term follow-up of patients returning to their home countries following treatment. Continuous exchange between the clinic in the home country and the clinic abroad that provided the care is crucial to gain long-term data and experience (96).

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