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Access to cross-border care and innovation for children and young people with cancer

Recommendations for the modernisation of EU rules on cross-border access to healthcare

INTRODUCTION AND BACKGROUND

Each year, more than 35,000 children and young people in Europe are diagnosed with cancer, and more than 6,000 young patients die of cancer[1]. Inequalities in access to treatment, care and research across Europe contribute to an estimated 20% gap in survival rates, with Eastern Europe countries facing the greatest challenges[2].

Because childhood cancers are rare complex diseases, they require highly specialised, multidisciplinary care and concentrated expertise. However, no single country can deliver the full range of optimal care, clinical trials and innovation on its own. **For children and young people with cancer, cross-border access to optimal, timely life-saving care, clinical trials and innovation is therefore a medical necessity, not a luxury. No matter where they live.**

Cross-border healthcare in the EU was first covered by Regulations (EC) Nos 883/2004 and 987/2009 on the co-ordination of social security systems ("the Regulations"). The EU's 2011 Cross-Border Healthcare Directive 2011/24/EU on the application of patients' rights in cross-border healthcare ("the Directive") and the creation of European Reference Networks, including for Paediatric Cancer (ERN PaedCan) were further major steps forward. By establishing patients' right to seek care in another Member State and pooling Europe's scarce paediatric oncology expertise into shared networks of specialised centres or units, these actions have set the scene for improving access to cross-border care for rare disease patients. Yet new evidence from the CATCH-Europe project[3] shows that families of children and adolescents with cancer, clinicians and academia still face slow, unclear and unequal procedures when it comes to access to care or innovation abroad. Up to three in four countries report unsuccessful attempts to access care abroad, most often due to financial barriers and complex authorisation rules; and half of all cross-border requests to join early phase clinical trials end in failure[4].

As the European Parliament is reviewing the rules on cross-border healthcare, Childhood Cancer International - Europe (CCI Europe) and the European Society for Paediatric Oncology (SIOPE) propose six concrete recommendations to ensure every child and young people with cancer in Europe, regardless of where they live, can access the best possible care, clinical trials and innovation.

POLICY RECOMMENDATIONS

1. Guarantee fast, transparent authorisation and reimbursement

Prior authorisation and reimbursement timelines under the current legislative set-up vary hugely between Member States - some decide within weeks, others within months - leaving families in financial uncertainty during a time-critical illness. A child's medical condition can change faster than administrative procedures, so delayed referrals reduce the chances of successful treatment.

[1] Cancer Today, 2023 Nov 30, https://gco.iarc.who.int/today/home
[2] Gatta G, Botta L, Rossi S, Aareleid T, Bielska-Lasota M, Clavel J, et al. Childhood cancer survival in Europe 1999-2007: results of EUROCARE-5--a population-based study. Lancet Oncol. 2014 Jan;15(1):35–47.
[3] 'Childhood cancer Access to Trials and Healthcare across Europe'. This project draws on data from 90 specialised hospitals (ERN PaedCan's activity), a survey of clinical-trial centres in 18 countries, and the lived experience of patient organisations in 26 countries.
[4] ITCC numbers.

Recommendation: Make cross-border referral and authorisation processes clear, fast, and transparent, with guaranteed timelines and reduced administrative burden - such as by setting maximum timelines for prior authorisation and reimbursement decisions.

2. Provide access to both care and clinical trials and innovative therapies

In paediatric oncology, clinical trials are part of standard care. More than 40% of children and adolescents with cancer in some western European countries are treated within a trial. In addition, for patients who no longer have access to curative standard treatments (those with refractory or relapsed malignancies), participation in early-phase clinical trials is the international standard of care. These trials can provide access to novel medicines which may prolong survival and improve quality of life when no other therapeutic options remain. Because these trials are rare and resource-intensive, they are organised in only a handful of European countries to centralise expertise and recruit enough patients, forcing families to travel abroad at great expense. Clinical trials covering innovative therapies, such as CAR-T cell treatments and precision medicines, are similarly restricted to select centres[5], and patients who need them cannot access or be reimbursed for treatment in another Member State.

Despite this evidence, cross-border participation in clinical trials is not addressed by EU legislation, and trials remain excluded from reimbursable care under the Directive - leaving sick children without a clear path to potentially life-saving treatment abroad.

Recommendation: Integrate clinical trials and access to innovative therapies in the application of EU cross-border healthcare legislation (currently governed by Directive 2011/24/EU and Regulations 883/2004 and 987/2009), such as by adapting the S2 pre-authorisation form to include an enlarged interpretation for access to clinical trials and experimental therapies.

3. Ensure predictable funding, including travel and living costs

Even when treatment itself is covered, families report having to pay upfront for travel, accommodation and lost income - costs that can determine whether a child receives life-saving treatment abroad at all. In practice, many families end up relying on charity funding to cover these costs, and sometimes even medical costs when these are not covered by reimbursement insurance. Cross-border care can mean uprooting family life for months: when siblings cannot accompany a sick child abroad, the separation causes significant emotional distress and family disruption that compounds an already devastating situation.

Recommendation: Ensure sustainable resourcing and insurance continuity through consistent authorisation processes, dedicated funding schemes, coverage of associated travel and accommodation costs, and families' protection against socio-economic disruptions in the lead-up to, during and after treatment.

4. Create national cross-border care navigator roles with allocated financing

National Contact Points, intended to guide families, may lack the resources, training and coordination to do so effectively. Patient organisations play an indispensable role by filling this gap informally (e.g., translating documents, coordinating logistics) many without proper funding or formal recognition.

Recommendation: Set up national cross-border 'navigators' formally integrating patient organisations as partners in guiding families through medical, legal and logistical steps.

[5] Teodora Lalova et al., 'Cross-Border Access to Clinical Trials in the EU: Exploratory Study on Needs and Reality', Frontiers in Medicine 7 (22 October 2020): 585722, https://doi.org/10.3389/fmed.2020.585722.

In addition, strengthen the role and expert staffing of National Contact Points, especially for all paediatric rare diseases.

5. Guarantee early, accessible, multilingual information

Language barriers were reported by families attempting cross-border care in the CATCH project. For instance, very few national websites offer clear, up-to-date guidance on rights and procedures.

Recommendation: Encourage Member States to provide accessible, multilingual and regularly updated information on specialised centres, networks, open clinical trials and reimbursement rights for both families and health professionals.

6. Foster sustainability of and strengthen cross-border networks, European organisations and research platforms.

ERN PaedCan aims to reduce inequalities in childhood cancer survival by providing equal access to high-quality, accessible, and cost-effective cross-border healthcare for children and young people with cancer. This network brings together 90 hospital institutions. Other networks and European organisations are active in paediatric cancers such as SIOPE, CCI Europe and ITCC[6] also play a key role and collaborate with ERN PaedCan, deserving recognition and funding.

Recommendation: Secure long-term, dedicated funding for paediatric cancer networks – an area where cross-border aspect is central and exchange of expertise is required for access to specialist care, clinical trials, and effective advocacy.

CONCLUSION

The objective of the European childhood cancer community is to cure more children and adolescents with cancer, to cure them better and to reduce inequalities. This is aligned with EU's vision as expressed through Europe's Beating Cancer Plan (EBCP), with its dedicated Section on Childhood Cancer, adding important momentum to address the critical needs of these patients by 2030 and beyond. None of this is achievable without modernised, patient and family-centred rules and streamlined implementation. Improving cross-border access to high-quality care and clinical trials is of the outmost importance to reduce inequalities in childhood cancer in Europe. CCI Europe and SIOPE therefore urge the European Parliament to take up these six recommendations as part of the ongoing revision of the rules on cross-border access to healthcare. Access to the best available care and research in Europe should not depend on where a child lives.

About this paper:

The recommendations laid down in this position paper are based on the CATCH-Europe project report, conducted jointly by the European Society for Paediatric Oncology (SIOPE), the European Reference Network on Paediatric Cancer (ERN PaedCan), the academic clinical trial network Innovative Therapies for Children with Cancer (ITCC), and the patient organisation Childhood Cancer International – Europe (CCI-Europe). This project aimed at studying the cross-border access to high- quality care, clinical trials and innovation for children and adolescents with cancer in Europe and making recommendations to improve the EU regulatory framework.

The CATCH-Europe report is currently available upon request and on SIOPE and CCI Europe's websites from September 2026.

[6] The Innovative Therapies for Children and Adolescents with Cancer (ITCC) consortium.

ABOUT EUROPEAN CHILDHOOD CANCER ORGANISATIONS

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 60 organisations in more than 30 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)**

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)**