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European Paediatric Cancer Community Recommendations for Improvement of Rules on Cross-border Access to Healthcare

INTRODUCTION AND BACKGROUND

Childhood Cancer International – Europe (CCI-E) and **the European Society for Paediatric Oncology (SIOPE)** welcome the European Parliament's ongoing review of the rules on cross-border access to healthcare through the Report 2025/2206 (INL). Our community has examined the implementation of the EU cross-border healthcare rules and the implications for children and young people with cancer through the CATCH-Europe project, conducted jointly with the European Reference Network on Paediatric Cancer (ERN PaedCan) and the academic clinical trial network Innovative Therapies for Children with Cancer (ITCC). The main conclusions and recommendations of the project are set out in this present joint position paper and have informed our present recommendations to the European Parliament Report, including its Annex.

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 and complex diseases, cross-border access to care, clinical trials and innovation is essential – not optional - to ensuring that all children and young people have the best possible chance of survival and quality of life.

Yet evidence from the CATCH-Europe project shows that families still face slow, unclear and non-uniform procedures when accessing care and research abroad: unsuccessful attempts to access specialist care in another Member State are reported in up to four countries, and half of all cross-border requests to join potentially life-enhancing early-phase clinical trials end in failure.

SIOPE and CCI-E have identified **seven priority areas** which require focused consideration during the revision of the current rules on cross-border healthcare. We detail below the rationale for each.

[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.

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PRIORITY AREAS FOR PAEDIATRIC CANCER COMMUNITY

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.

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. Extend cross-border healthcare rules to clinical trials and innovation

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[3], and patients who need them require access and reimbursement of 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.

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.

[3] 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.

4. Protection of social rights for families of patients receiving cross-border care

Parents of children with cancer are frequently required to relocate, sometimes for extended periods, to access specialised treatment or clinical trials only available in another Member State. Where this relocation requires establishing formal domiciliation abroad, it can trigger the loss of home-country social security coverage, unemployment benefits, or other residence-linked entitlements. This creates a serious disincentive for families to seek life-saving care abroad and effectively penalises them for exercising the very rights this Directive is meant to guarantee. Article 5 of the Directive currently sets out the responsibilities of the Member State of affiliation towards patients receiving cross-border healthcare (i.e., reimbursement, information, medical follow-up and access to medical records) but is silent on the preservation of patients' and accompanying family members' social security status at home.

Recommendation: Amend the Directive to ensure that patients, and where relevant their accompanying family members or caregivers, do not lose their social security entitlements, residence-based rights or benefits in the Member State of affiliation as a result of a temporary stay or change of residence in another Member State in the framework of this Directive. This amendment ensures that necessary cross-border treatment does not come at the cost of a family's social protection at home.

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. Create national cross-border care navigator services for families 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 of them 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. In addition, strengthen the role and expert staffing of National Contact Points, especially for all paediatric rare diseases.

7. Ensure the sustainability of cross-border networks, European organisations and research platforms in paediatric oncology

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; they also play a key role and collaborate with ERN PaedCan.

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.

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 over 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)**