August 2025

No Child Left Behind

Creating Equal Access to Care and Research in Childhood Cancer through the EU 2028–2034 Budget

EXECUTIVE SUMMARY

The European Society for Paediatric Oncology (SIOPE) and Childhood Cancer International - Europe (CCI-E), urge the European Union to maintain **childhood cancer as a clear priority within health and research funding** in the upcoming Multiannual Financial Framework (MFF) 2028–2034.

Childhood cancer remains a public health burden as the leading cause of death by disease in children over 1 year old in Europe[1], with over **6,000 lives lost annually**[2]. Meanwhile, **500,000 young survivors**[3], growing by **12,000 each year**[4], face lifelong physical and psychological late effects - yet most treatments used today were never designed for children.

The EU budget allocation to childhood cancer is a relatively small proportion (circa. 0,18 of the EU Horizon and EU4 Health budget)[5] which **can generate a major, potentially lifesaving impact** by supporting treatment access, clinical research, survivorship programmes, and collaborative innovation. Building on the progress enabled by Europe's Beating Cancer Plan and the EU Cancer Mission, sustained **EU investment is essential to close persistent gaps in the areas of drug development, access to timely and quality care to every child and no or fewer toxic late effects.**

Priority Areas to Address under MFF 2028–2034

To address these challenges, the EU must act across four priority areas in the MFF 2028-2034:

1. **Boost Drug Development and Access to Innovation in Childhood Cancer**
2. **Implement Childhood Cancer Care Networks and Infrastructures**
3. **Unlock Opportunities through Data Sharing and AI Tools**
4. **Real patients, real voices: Operating Grants for Patient Organisations and Learned Societies**

The MFF 2028–2034 offers a strategic opportunity for the EU to scale up efforts in the area of childhood cancer, making a high-impact investment and accelerating research to safeguard the wellbeing of Europe's next generation. **These elements will reinforce the political resolve across Europe to restore its competitive edge and ensure prosperity**.

For more information, please refer to the full paper below.

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[1] 'Cancer Today'.

[2] 'Cancer Today'.

[3] Hjorth et al., 'Survivorship after Childhood Cancer'.

[4] Kalsbeek et al., 'The PanCareFollowUp Care Intervention'.

[5] 'Cancer Projects Dashboard | Knowledge for Policy'.: https://knowledge4policy.ec.europa.eu/cancer/cancer-projects-dashboard_en

INTRODUCTION

Childhood cancer remains the leading cause of death by disease in children over one year old in Europe, with over 6,000 deaths and 35,000 diagnoses each year[6]. To support actions tackling the public health impact of childhood cancer, the EU has allocated vital support via EU's health and research funding. This funding has enabled high impact projects and initiatives working towards improving access to care, enabling collaborative research, and supporting survivorship.

Through policy tools including the Europe's Beating Cancer Plan and the EU Cancer Mission, and targeted investments through programs such as EU4Health and Horizon Europe, the EU has shown that it can be a catalyst for real change in childhood cancer. Examples of this impact include:

- Contributing to **twinning projects** with the aim of exchanging expertise and skills between childhood cancer health professionals (e.g., TREL Project);
- **Improving quality of survivorship and mental health** (EU-CAYAS-NET);
- Supporting the future uptake of clinical **AI applications** (UNICA4EU);
- Developing **Public Private Partnerships** that upholds Paediatric Oncology Drug Development (ITCC-P4);
- **Support in accessing standard of care treatment European Reference Network for Paediatric Cancer (**ERN PaedCan);
- And other important initiatives across the 35 EU-funded projects with a focus on childhood cancer (e.g., JANE, ECHos, Network of Comprehensive Cancer Centres).

As a rare disease with a high public health burden, with stark inequalities in survival and access to care and research across Europe[7], Childhood cancer must remain a priority with EU funding and health policy instruments. Addressing these disparities is not only a humanitarian imperative but also a socioeconomic necessity. As Europe's population ages and birth rates decline, ensuring long-term health and societal participation of survivors is essential[8].

The collaborative nature of paediatric oncology - with its strong links between research and clinical practice, and its experience of cross-border collaborations - makes it an ideal area where EU-level coordination can continue to deliver clear added value. Investing in childhood cancer also strengthens EU health systems, competitiveness, and innovation capacity.[9] There is a strong need to accelerate equal access to standard of care treatment and the childhood-cancer specific research and innovation capabilities across Europe, with focus on areas of urgent unmet medical needs, insufficient research capability or areas of insufficient commercial interest.

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[6] 'Cancer Today'.
[7] Gatta et al., 'Childhood Cancer Survival in Europe 1999-2007'.
[8] Joint Research Centre, *Low Fertility in the EU: A Review of Trends and Drivers*.

Significant gaps remain that only the EU is uniquely positioned to address, considering the particularities of childhood cancers:

- **New hope, not old drugs.** Drug development for children lags far behind adults - just 16 paediatric cancer drugs approvals in the last 10 years in contrast with over 150 for adults.
- **The right treatment, at the right time, for every child.** Significant disparities remain in access to diagnostics, treatments, care and research – especially in Eastern Europe - leading to a 20% survival gap across Europe[10].
- **Cure must mean full recovery.** Most drugs used to treat childhood cancer are highly toxic, causing long-term physical and mental health effects such as cardiovascular damage, fertility issues, depression, and anxiety.

No single country can tackle childhood cancers' challenges alone. The upcoming Multiannual Financial Framework (MFF) 2028–2034 offers a critical opportunity to sustain this momentum. With strategic and sustained investment, the EU can address the persistent gaps in care, research, and survivorship support.

THE UNMET NEEDS OF CHILDHOOD CANCER

1. TOO FEW MEDICINES, TOO MUCH TOXICITY: SUPPORTING ACCESS TO RESEARCH & INNOVATION

Despite medical progress in adult oncology, drug development for childhood cancers remains alarmingly limited. Since the introduction of the EU Paediatric and Orphan Regulations[11], only 16 cancer medicines have been approved for paediatric use in the past decade, compared to over 150 for adults[12]. Most treatments used in children are repurposed from adult indications, often used off-label, and associated with severe toxicity.

There is also a lack of commercial interest in developing medicines for ultra-rare paediatric cancers, leading to decades-long stagnation for diseases with some of the highest mortality rates. Notably, there has been zero new treatments developed in some childhood cancers as demonstrated by the fact that for certain CNS tumours or certain sarcomas, which account for approximately one-third of childhood cancer deaths (27.2%) in children aged 0–14 years, no single novel drug has been developed in the last 15 to 20 years[13]. For malignancies such as diffuse intrinsic pontine glioma (DIPG), high-grade glioma and high-risk neuroblastoma, patient outcomes remain tragic with limited improvement over the last 30 years[14].

The Draghi report on the future of European competitiveness calls on the EU to increase its attractiveness for conducting clinical trials and to accelerate access to innovative medicines[15]. Childhood cancer presents a compelling opportunity to act on this recommendation.

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[10] Gatta et al., 'Childhood Cancer Survival in Europe 1999-2007'.

[11] The EU Paediatric Regulation (Regulation (EC) No 1901/2006) entered into force on January 26, 2007. The Orphan Regulation (Regulation (EC) No 141/2000) entered into force in 2000.

[12] Vassal et al., 'Impact of the EU Paediatric Medicine Regulation on New Anti-Cancer Medicines for the Treatment of Children and Adolescents'. The Lancet Child & Adolescent Health Volume 7, Issue 3, March 2023, Pages 214-222.

[13] Ibid.

[14] Vassal et al., 'Orphan Drug Regulation: A missed opportunity for children and adolescents with cancer', vol. 84, p149-158, October 2017.

[15] Draghi, Mario, *The Future of European Competitiveness, Part A | A Competitiveness Strategy for Europe*.

Academic-led research has played a pivotal role in achieving average five-year survival rates of 80% in Europe[16], with facilitating access to clinical trials in some cases considered as best practice. Yet, significant challenges persist:

- Early-phase clinical trials, critical for children with relapsed or refractory cancers, are underfunded[17] and logistically complex for various reasons including low-patient volume;
- Academic networks, such as Innovative Therapy for Children and Adolescents with Cancer (ITCC) and SIOPE Clinical Research Council, **that run the clinical trials** necessary to improve survival and reduce long-term toxicity of treatments require support.

Published literature indicates that childhood cancer has received considerably less public funding in Europe than in regions like North America[18]. To contribute to the EU's status as a global leader in research and innovation, focusing investment in childhood cancer can close the innovation gap and strengthen innovation in an area of unmet needs. Supporting the European childhood cancer clinical trial networks can contribute to increasing access to innovation, improving survival rates and reduce long-term toxicity of treatments.

Supporting innovation in childhood cancer is not only about increasing survival rates but also about improving the quality of life for survivors. Ensuring quality of life after treatment is equally vital. Europe is home to over 500,000 survivors of childhood, adolescent, and young adult (CAYA) cancer[19], with 12,000 more each year[20]. Yet two-thirds of survivors psychosocial and physical late effects, including cardiovascular complications, fertility problems, cognitive impairments, and psychological distress.

Many cancer survivors lack access to structured follow-up care, and few countries offer dedicated survivorship clinics or life-after-treatment medical pathways. Despite new attention under Europe's Beating Cancer Plan, support for survivorship remains fragmented, underfunded, and inconsistently implemented.

POLICY RECOMMENDATIONS: BOOST DRUG DEVELOPMENT & ACCESS TO INNOVATION

- EU investment in this area must be strengthened to unlock breakthrough innovations not only in curative treatments that improve survival but also in therapies that reduce long-term toxicity.
- Support and expand European childhood cancer networks - such as ITCC and SIOPE Clinical Research Council - which run the clinical trials essential to improving survival and reducing long-term treatment toxicity.
- Provide continued EU funding for clinical trials, academic clinical trial networks, and public private partnership projects to support research and innovation in childhood cancer.
- Facilitate cross-border access to academic clinical trials, especially to early phase trials, which are critical for children with a life-threatening refractory or relapsed malignancy in Europe.

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[16] Gatta et al., 'Childhood Cancer Survival in Europe 1999-2007'.; Macy et al., 'Novel Therapies for Pediatric Cancers'; Valsecchi et al., 'Clinical Trials in Childhood Cancer'.; Valsecchi et al., 'Clinical Trials in Childhood Cancer'.

[17] Joseph et al., 'Clinical Trials in Children'.

[18] Loucaides et al., 'Global Public and Philanthropic Investment in Childhood Cancer Research'.

[19] Hjorth et al., 'Survivorship after Childhood Cancer'.

[20] Kalsbeek et al., 'The PanCareFollowUp Care Intervention'.

- Invest in follow-up care models, including dedicated medical consultations and long-term health monitoring.
- Integrate psychosocial support throughout the treatment and recovery journey and promote survivorship research to understand and mitigate late effects.

2. UNEQUAL ACCESS TO CARE ACROSS EUROPE

Children and young people with cancer across Europe experience inequalities in access to standard diagnostics, treatment, care and participation in research. While some Member States benefit from advanced protocols and infrastructure, others - particularly in Eastern Europe - lag behind, contributing to a 20% survival gap across European countries[21].

When innovative therapies are developed, they are not introduced evenly across countries. Newly approved medicines often face delays in national Health Technology Assessment (HTA) processes and reimbursement decisions, which hinders timely and equitable access. Even when treatments are authorised at EU level, their rollout into clinical practice remains inconsistent[22].

In addition, families seeking cross-border care often encounter significant administrative, legal, and financial obstacles. The complexity of reimbursement systems, lack of clear guidance, and logistical burdens create further inequities in access to potentially life-saving treatments beyond national borders.

EU structures like the European Reference Network for Paediatric Cancer (ERN PaedCan) and twinning initiatives (e.g., TREL, SCARLET) have shown success in reducing disparities. By addressing the financial sustainability of these initiatives and supporting their integration into national health systems, the EU can continue to tackle inequalities in access to high quality and standard of care treatment.

Enhancing the sustainability and integration of ERN PaedCan into national healthcare systems is an important future consideration to minimise inequalities in access to high quality care and standard treatment. In addition, the differences in the organisation of care in paediatric and adult cancer settings should be recognised in EU initiatives. Paediatric cancer care requires specific support from EU initiatives, including the EU Network of Comprehensive Cancer Centres (Europe's Beating Cancer Plan) and Comprehensive Cancer Infrastructures (EU Mission on Cancer).

To ensure children benefit from these frameworks, we propose recognising and expanding specific Comprehensive Childhood Cancer Infrastructures within ERN PaedCan. This would strengthen ERN PaedCan's capacity to deliver care, education, training to healthcare professionals and integrate research and innovation. In addition, twinning and networking projects (e.g., TREL and SCARLET) should also be scaled within these networks and infrastructures to improve paediatric access to paediatric cancer diagnosis, treatment and research across Member State.

POLICY RECOMMENDATION: IMPLEMENT CHILDHOOD CANCER CARE NETWORKS AND INFRASTRUCTURES

To continue making progress in providing equal access to high quality and standard of care across the EU, we propose:

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[21] Gatta et al., 'Childhood Cancer Survival in Europe 1999-2007'.

[22] Schoot et al., ‘Market Access to New Anticancer Medicines for Children and Adolescents with Cancer in Europe’.

- Ensure long-term sustainability and national integration of ERN PaedCan to reduce inequalities in access to high quality care and standard of care treatment.
- **Recognise and expand specific Comprehensive Childhood Cancer Infrastructures** within the existing ERN PaedCan structure, to support provision of care, education and training to healthcare professionals and integrate research and innovation capabilities for all children and young people in Europe.
- Expand successful twinning projects (e.g TREL, SCARLET) to reduce regional gaps in diagnosis, care and innovation cancer centres in various Member States.
- Support the development of National Cancer Mission Hubs (NCMHs) and initiatives like JARDIN to enhance coordination.
- Remove cross-border care barriers by simplifying reimbursement systems, supporting patient travel and accommodation, and clarifying legal entitlements.
- Promote survivorship research to understand and mitigate late effects.

3. ENABLING DATA SHARING TO ENHANCE CARE AND RESEARCH CAPABILITIES

High-quality data is essential to improve care, personalise treatment, and accelerate research. Yet, paediatric cancer data in Europe remains siloed and difficult to access. Since the introduction of GDPR, sharing real-world and clinical data across borders has become more difficult[23]. The implementation of a robust EU regulatory framework through EHDS is eagerly awaited to unlock greater opportunities for research and care delivery.

In addition, while large data sets exist in Europe - often from academic trials - they are underutilised and fragmented due to regulatory and technical barriers. Access to data for research is therefore limited and complex, especially for real world data (RWD).

Initiatives related to paediatric cancer care and research, like UNICA4EU and UNCAN.eu have demonstrated the transformative potential of AI and federated data systems.

- The UNICA4EU project has mapped existing AI applications in childhood cancer and highlighted how these technologies can enhance care pathways across the EU.
- The EU's work on the UNCAN.eu platform - a European Federated Data Hub designed to provide access to high-quality cancer research data - will be a key driver in this effort. UNCAN.eu has the potential to establish a vital European infrastructure that supports access to comprehensive paediatric cancer data for research and innovation[24].

POLICY RECOMMENDATION: UNLOCK OPPORTUNITIES THROUGH DATA SHARING AND AI TOOLS

- Support effective EHDS implementation across Member States with clear frameworks to improve data sharing for research of rare diseases, including childhood cancers.
- Utilise the potential of the UNCAN.eu platform to build and fund a European infrastructure that may facilitate access to comprehensive childhood cancer data for care and research.

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[23] Vassal et al., 'The Impact of the EU General Data Protection Regulation on Childhood Cancer Research in Europe'.

[24] Vassal, 'UNCAN.Eu, the European Platform to Understand Cancer, and Childhood Cancers'.

- Continue exploring venues to understand childhood cancers namely ensuring comprehensive, secure and high-quality data aggregation across European countries and the development of AI-driven data solutions.
- Scale genomic sequencing as a promising area for research for rare diseases and support cross-border research using real-world data.

4. REAL PATIENTS & CLINICIANS, REAL VOICES

Non-governmental organizations working in the health sector such as patient organisations and learned societies play a critical role in shaping care, raising awareness, guiding research priorities, and supporting families. Without sustained support, their contributions risk being diminished or lost. Operating grants and EU-funded projects are an opportunity for civil society to contribute to implementing the objectives of the EU4Health Programme, by building awareness, contributing to EU funded projects and supporting evidenced based policy making, by generating evidence on the specific needs in childhood cancer care and research.

Civil society actors, particularly patient organizations, play a key role in supporting and complementing EU policies. They work on fostering alignment in paediatric cancer care within the EU but also among the EU and non-EU neighbourhood and candidate countries, by developing and promoting evidence-based recommendations such as the *European Standards of Care for Children with Cancer*[25] and research on anticancer drug shortages.

POLICY RECOMMENDATION: SECURE OPERATING GRANTS AND EU FUNDED PROJECTS FOR CIVIL SOCIETY

- Guarantee continued EU4Health operating grants for healthcare civil society, including childhood cancer organisations.
- Enable patient organisations and learned societies to contribute independently and meaningfully to EU-funded projects.
- Facilitate the role of patient organisations and learned societies in generating evidence, bridging care gaps, and supporting policy development.

CONCLUSION

EU-level support is instrumental to ensure that the urgent needs of childhood cancer patients and survivors are not overlooked and instead become an integral part of all relevant funding programmes.

The MFF 2028–2034 represents a **pivotal opportunity for the EU to build on its leadership in childhood cancer, reduce cross-border inequalities, close the innovation gap by accelerating research, and invest in a healthier next generation**. Proportionally small, targeted investments can generate life-saving impact across Europe's paediatric oncology landscape. By addressing today's unmet needs with coordinated, strategic action, the EU can ensure that every child with cancer - regardless of where they live - has equal access to timely diagnosis, quality care, innovative treatments, and a future beyond cancer.

No child should be left behind.

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[25] https://ccieurope.eu/diagnosis-treatment-care/

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: 67 organisations in 34 European countries are members of CCI-E. CCI Europe works together with all relevant stakeholders for the same aim: help children and adolescents with cancer to be cured, with no - or as few as possible - long term health problems/late effects. **(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)**