SIOP Europe
the European Society for Paediatric Oncology

Prioritising Childhood Cancer Care and Research in the Multiannual Financial Framework 2028-2034

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Executive Summary:

The European Society for Paediatric Oncology (SIOP Europe or SIOPE), the only pan-European organisation representing all professionals working in the field of childhood cancers, urges the European Union to continue prioritising childhood cancer as part of the upcoming Multiannual Financial Framework (MFF) 2028–2034. 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 access to care, innovation, and survivorship support across Member States.

Why Continued EU Investment Matters:

- Childhood cancer remains the leading cause of disease-related death in children over one year old in Europe.
- Despite its small share of EU health and research budgets (~1%), investment in childhood cancer contributes to life-saving outcomes through initiatives like ERN PaedCan, public private partnerships supporting drug development, and survivorship programs (e.g. EU-CAYAS-NET).
- Significant disparities remain in access to diagnostics, treatments, and research, particularly in Eastern Europe, contributing to a 20% survival gap across countries.

Policy Recommendations for MFF 2028–2034:

- Support the European childhood cancer networks (e.g ITCC, SIOPE Clinical Research Council) that lead the way in innovation for childhood cancers.
- Address the gaps and needs in access to cross border healthcare and research for childhood cancer patients and their families.
- Recognise and expand specific Comprehensive Childhood Cancer Infrastructures within the existing ERN PaedCan structure to reduce inequalities in access to standard of care treatment and research/innovation.
- Promote the sustainability and ongoing implementation of ERN PaedCan to reduce inequalities in access to high quality care and standard of care treatment.
- Advance Data Sharing by supporting the implementation of the European Health Data Space, building federated data infrastructures that address the needs of childhood cancer and leveraging AI and big data tools.
- Support NGOs through Operating Grants, enabling organisations like SIOPE to contribute evidence- based expertise and support EU health policy objectives.

To ensure all children and young people with cancer in Europe have equal access to high-quality diagnosis, treatment, and survivorship support, childhood cancer must remain a priority in EU funding and policy frameworks. The MFF 2028–2034 presents a crucial opportunity to reinforce the EU's leadership in paediatric oncology, drive innovation, and reduce inequalities—safeguarding the health and potential of future generations. Collectively, these elements will reinforce the political resolve across Europe to restore its competitive edge and ensure prosperity.

Introduction

The spotlight on childhood cancer demonstrated by the EU in Europe's Beating Cancer Plan in coordination with the EU Cancer Mission, facilitated by the EU's health and research budget allocation to childhood cancer has enabled numerous projects with concrete outcomes. Positive impacts were seen from EU funded projects in recent years[1] in areas including:

- Twinning to enable transfer of 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)
- IHI Public Private Partnership supporting Paediatric Oncology Drug Development (ITCC-P4)
- Support in accessing standard of care treatment (European Reference Network for Paediatric Cancer)
- And other important initiatives across the 35 funded projects with a focus on childhood cancer

The EU budget allocation to childhood cancer is a relatively small proportion (circa. 1% of the EU Horizon and EU4 Health budget) which **can generate a major, potentially life saving impact.**

Childhood cancer should continue to be seen as a priority area, due to their individual rarity and high overall burden in Europe as well as demonstrable inequalities in access to treatment and research, and survival rates amongst EU countries. **The remaining gaps for an equal chance of high quality survival for each children and young person with cancer with cancer in Europe should be addressed.**

At a time when birth rates are falling in the EU[2], ensuring high cure rates and an optimal long-term healthy survivorship experience can **safeguard this future generation's contributions to society and economy.**

The collaborative nature of the paediatric oncology community highlights how childhood cancer continues to be an area where the EU can achieve more than Member States acting alone and support competitiveness, particularly in terms of closing the innovation gap. Owing to strong cross-border, multidisciplinary and international academic-driven research, as well as the link between clinical work and basic/translational research, the diagnosis and treatment of childhood cancer has improved[3]. 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, insufficient research capability or areas of insufficient commercial interest.

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[1] 'Cancer Projects Dashboard | Knowledge for Policy'.

[2] Joint Research Centre, 'Low Fertility in the EU: A Review of Trends and Drivers'.

[3] Desandes and Stark, 'Epidemiology of Adolescents and Young Adults with Cancer in Europe'.

The Unmet Needs in Childhood Cancer

Childhood cancer remains the number one cause of death by disease in children over one year old in Europe, with 35,000 cases diagnosed and 6,000 deaths annually[4]. Inequalities in access to diagnostics, treatment, care and research protocols across Europe contribute to an estimated 20% gap in childhood cancer survival rates, with Eastern European countries facing challenges[5]. The Childhood, Adolescent, and Young Adult (CAYA) cancer survivor population is estimated at 500,000[6], increasing by 12,000 each year[7], with two-thirds experiencing late effects. This burden is driven by a number of key issues.

1. Drug Development & Access to Innovation

Today, neither the EU Paediatric nor the EU Orphan Regulations have succeeded in significantly improving young cancer patients' chance of survival. Notably, over the last ten years, only 16 anticancer medicines have been authorised for a specific paediatric cancer indication, in contrast to over 150 for adult cancers[8].

Most of the treatments currently used for paediatric cancers have been developed to treat adult cancers. Additionally, off-label use of anti-cancer medicine is very common due to lack of specific paediatric cancer drugs. This leads to a vast amount of adverse side effects due to high levels of toxicity of treatments.

2. Access to Treatment & Care

Children and young people with cancer across Europe experience inequalities in access to the best available standard diagnostics, treatment, care and research protocols. Where there are new treatments developed, newly approved medicines are not introduced into clinical practice in all Member States or at the same pace. The uptake of paediatric anti-cancer medicines across Member States is often delayed due to variability in Health Technology Assessment decisions, leading to delays in access to new anti-cancer medicines[9]. Accelerated introduction of new medicines in standard treatment and equal access to therapies is urgently needed to treat more young patients with cancer.

The strong need to reduce inequalities in access to high quality care and standard treatment can be addressed by existing cross border networks in paediatric oncology, including the European Reference Network for Paediatric Oncology (ERN PaedCan). Enhancing the sustainability and integration of ERN PaedCan into national healthcare systems is an important future consideration. In addition, the differences in the organisation of care of paediatric and adult cancer patients need recognition and specific supports from EU initiatives, including the EU Network of Comprehensive Cancer Centres

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[4] 'Cancer Today'.

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

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

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

[8] Vassal, de Rojas, and Pearson, 'Impact of the EU Paediatric Medicine Regulation on New Anti-Cancer Medicines for the Treatment of Children and Adolescents'.

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

launched by the Europe's Beating Cancer Plan and Comprehensive Cancer Infrastructures launched by the EU Mission on Cancer. To ensure paediatric cancer patients benefit from access to ongoing EU initiatives, we propose that the concept of specific Comprehensive Childhood Cancer Infrastructures be recognised and expanded upon within the European Reference Network for PaedCan (ERN PaedCan). This would further enhance the capacity of ERN PaedCan to provide care, education and training to healthcare professionals, as well as to integrate research and innovation capabilities. In addition, twinning and networking projects (e.g TREL and SCARLET) could be utilised to strengthen equal access to paediatric cancer diagnosis, care, treatment and research at Member State level.

3. Late Effects

Cancer diagnosis can have a physical and psychosocial impact on the patient, both throughout treatment and beyond. Late-effects may occur as physical side-effects, including cardiovascular disease, organ and skin alterations, fertility problems, and cognitive impairment as well as mental health issues such as depression and anxiety.

There remains an unmet need for drugs with novel mechanisms of action that not only improve survival but also reduce the acute and long-term burden of therapy. In addition, these side-effects also underline the need for the systematic inclusion of psychosocial care in disease treatment and follow-up care. The Europe Beating Cancer Plan placed a much-needed spotlight on these issues through the launch of various initiatives aimed at improving survivorship, which should be maintained in the long-term. Only in this way the numerous survivors of childhood cancers can live a full and live and participate in society and economy.

4. Supporting Access to Research and Innovation

The Draghi report on the future of European competitiveness makes the case that the EU should aim to boost its attractiveness for conducting clinical trials and to expedite access to markets for novel medicines[10]. When assessing the clinical trial landscape in childhood cancer, it is important to understand the vital role of academic clinical trials. The collaborative academic-driven efforts of the paediatric oncology community have contributed to reaching 5-year survival rates of up to 80%[11]. Early phase academic clinical trials provide the opportunity to access potentially lifesaving innovative treatments in the case of relapsed or refractory malignancies. Due to the methodological challenges with running clinical trials for children and young people with cancer, collaborative cross-border clinical trial networks in paediatric oncology, such as ITCC and SIOPE's Clinical Research Council, are important fora for driving this research. At a time when there is 10 times less public funding is allocated to childhood cancer research in Europe than in other regions[12], EU support of research and innovation should be strengthened in priority areas such as childhood cancer. Supporting the European childhood cancer clinical trial

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

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

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

networks can contribute to supporting access to innovation, improving survival rates and reduce long-term toxicity of treatments.

5. Enabling data sharing to enhance care and research capabilities

Childhood cancer health and/or research data sharing had become more difficult since the GDPR's entry into force[13]. The implementation of a robust EU regulatory framework through the European Health Data Space (EHDS) is eagerly awaited to unlock greater opportunities for research and care delivery. Currently in Europe there are already existing and maintained large childhood cancer databases, mainly from academic trials. However, this data is often fragmented and access for research is limited and complex, especially for real world data. To address these silos there is a need to consider how strategic approaches to AI and big data can unlock new frontiers in paediatric cancer care and research.

Big data and Artificial Intelligence (AI) hold great potential to unlock new frontiers in paediatric cancer care and research. The UNICA4EU project mapped the existing AI applications for childhood cancer and shed light on how AI can be used help improve care pathways in the EU.

The work of the EU on the UNCAN.eu platform, a European Federated Data Hub to provide access to high-quality cancer research data in order to better understand cancer and drive innovation will be an important driver for this work. Due to it's consideration of childhood cancers, UNCAN.eu has the potential to build an important European infrastructure that may facilitate access to comprehensive childhood cancer data for research[14].

Policy Recommendations: How Childhood Cancer can be a priority in the MFF 2028-2034?

1. Enhance Drug Development and Innovation in Childhood Cancer

    - The new Multi-Annual Financial Framework (MFF) is an opportunity for the EU to strengthen its position as a leader in childhood cancer research globally and prioritise their efforts in an area where EU action is more effective than Member States acting alone . This will align with the EU's long term ambition in reducing inequalities in access to childhood cancer care and improving survivorship and strengthen right-based approaches and competitiveness by investing in children – our future.
    - **Support the European childhood cancer networks (e.g ITCC, SIOPE Clinical Research Council) that run the clinical trials** necessary to improve survival and reduce long-term toxicity of treatments.

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

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

- Need for continued EU funding for **clinical trials, academic clinical trial networks, and public private partnership projects** to support research and innovation in childhood cancer as an area of limited commercial attractiveness.
- **Facilitating cross-border access to academic clinical trials**, especially to early phase trials, is essential to assure equal access to innovation for all childhood cancer patients with a life-threatening refractory or relapsed malignancy in Europe

2. Implement Childhood Cancer Care Networks & Infrastructures

- **Promote the sustainability** and ongoing implementation of **ERN PaedCan** to reduce inequalities in access to high quality care and standard of care treatment.
- **Utilise the concept of twinning projects** between childhood cancer centres in the EU to reduce inequalities in access to high quality care and innovation. Previous and ongoing projects (e.g TREL and SCARLET) have established valuable partnerships between centres in various Member States. Expanding twinning and networking projects would strengthen equal access to paediatric cancer diagnosis, care, treatment and research/innovation at Member State level.
- **Recognise and expand specific Comprehensive Childhood Cancer Infrastructures** within the existing ERN PaedCan structure. This would further enhance the capacity of ERN PaedCan to provide care, education and training to healthcare professionals and integrate research and innovation capabilities for all children and young people in Europe.
- Support for **enhanced national implementation of EU initiatives at the national Member States level**, for paediatric cancer patients to further benefit, including the JARDIN Joint Action and the National Cancer Mission Hubs (NCMHs) operating at **national, regional, and local levels**
- **Improve access to cross-border care under existing EU legislation,** by addressing barriers such as complex reimbursement and legislative procedures, funding for patient and family travel and accommodation, and improved information on healthcare rights for treating physicians, patients and their families.

3. Ensure EHDS Implementation and Data Initiatives unlock greater opportunities for childhood cancer

- The **effective implementation of the European Health Data Space** is vital to advancing cross-border research and improving data sharing on rare cancers like those in children.

   - Explore options for scaling up **genome sequencing** as a promising area for research for our rare diseases.
   - Continuing 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.**
   - Utilise the potential of the UNCAN.eu platform to build a European infrastructure that may facilitate access to comprehensive childhood cancer data for care and research

4. EU Operating Grants for Non-Governmental Organisations
   - Ensure the availability of operating grants to support NGO's in the health sector to work **independently and uninfluenced as civil society actors.**
   - These grants are an opportunity for organisations such as SIOPE 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 the generating evidence on the specific needs in childhood cancer care and research.

Conclusion

The EU must continue prioritising childhood cancer under the new MFF and future EU Health and Research initiatives. 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. With continued investment, collaboration, and innovation in this area of unmet needs, the EU will be more competitive and can continue building a strong European Health Union where all children and young people with cancer have equal access to high quality care, diagnosis and treatment, and the same hope of survival and healthy productive lives, regardless of where they live.