

SIOP Europe the European Society for Paediatric Oncology

SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)

A European Cancer Plan for Children and Adolescents



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Acknowledgements

SIOP Europe has benefited from EU Project funding for the following initiatives:





SIOP Europe works in partnership with the following organisations and platforms :

Childhood Cancer International EUROPE	CCI Europe (Childhood Cancer International – Europe)
The future of cancer therapy	EORTC (European Organisation for Research and Treatment of Cancer)
ESGO European Society of Gynaecological Oncology	ESGO (European Society of Gynaecological Oncology)
COOD SCENCE RETER MERCINE REST PRACTICE	ESMO (European Society for Medical Oncology)
Europan of Contracting Factoria	ESO (European School of Oncology)
european cancer DBAAKIKATON	European Cancer Organisation
	PanCare (The Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer)
SOCIÉTÉ INTERNATIONALE DONCOLODIE PÉCHATRIDUE UNITERNATIONAL SOCIETY OF FACILITATION AL SOCIETY OF FACILITATION CONCOLOGY	SIOP International (International Society of Paediatric Oncology)

Platforms:





SIOP Europe President and CEO Message

It has been 6 years since the launch of the SIOP Europe Strategic Plan in 2015, which defined our priorities for 2015-2020. At the end of 2019 /beginning of 2020, the SIOP Europe Board reviewed our progress against these objectives and reflected upon what has been achieved, what remains a priority and which new initiatives should be launched for the coming 5 years.

This Report and Strategic Plan Update summarises the outcome of this review and details our objectives and aspirations for the next 5 years (2021-2026).

The release of the Report has been delayed due to the impact of the COVID-19 pandemic, which had consequences for all of us, both personally and professionally. We are grateful to all our members and to those in the community who collaborated on the objectives, activities and projects, and have contributed to the contents of this Report.

This 2021-2026 Updated Strategic Plan was approved by the Board on 8 September 2021.

SIOP EUROPE MISSION:

To ensure the best possible care and outcome for all children and young people with cancer.

OUR OBJECTIVE:

Beating childhood cancer: tackle inequalities and increase the quality of life for survivors.

SIOP Europe's Strategic Plan Update (2021-2026) is an important refresh of our key objectives and I am enthusiastic to engage with our community in its delivery. Our Board Members are eager to collaborate with all our members and partners to accomplish our mission for our community of children and young patients with cancer. — Prof Pamela Kearns (SIOP Europe President)

The voice from our community and our Board Members has never been more vital. As we continue to face the reality of cancer remaining the leading cause of death of children beyond one year of age, as well as the growing number of survivors in Europe, SIOP Europe draws on many years of leadership and the respected intellectual capital of its Board Members, members and partners. We are very grateful for the dedication and efforts of everyone.

SIOP Europe has great potential to inform and lead as a united profession of paediatric haemato-oncologists and healthcare professionals voicing the views of physicians and patients across Europe. We are a community determined to have the best possible care and outcomes for all children and young people affected by cancer in Europe. Together with our members, community and partners, we are striving for a brighter future for children and young adolescents with cancer.



Prof Pamela Kearns SIOP Europe President



Samira Essiaf SIOP Europe Chief Executive Officer





Executive Summary

Each year, more than 35,000 children and young people are diagnosed with cancer and more than 6,000 young patients die of cancer. Over 500,000 long-term survivors of childhood cancer live in Europe today and two thirds of them experience long-term health and psycho-social problems due to their disease.

SIOP Europe is the only pan-European organisation representing clinical professionals working in the field of childhood cancers, currently counting over 2,300 members across 35 European countries and continues to grow.

SIOP Europe's Mission is to ensure the best possible care and outcome for all children and adolescents with cancer in Europe. To achieve this goal, SIOP Europe is addressing the main challenges faced in European paediatric oncology through a multidisciplinary and pan-European perspective.

In 2015, within the European Network for Cancer research in Children and Adolescents (ENCCA), SIOP Europe and the European paediatric haematology-oncology community launched a long-term sustainable Strategic Plan. The Plan was a consensus document that defined the key future efforts and initiatives of the paediatric cancer community in Europe.



The Strategic Plan set the overall goals as:

- To increase the cure rate for young people who have a cancer with a poor prognosis.
- > To increase the quality of life for survivors of childhood cancer

The strategy pivoted around seven objectives of equal importance and the joint commitment by all stakeholders was crucial to support its implementation. Towards achieving these goals, SIOP Europe has been working closely with the European Clinical Trial Groups (ECTGs) and the National Paediatric Haematology Oncology Societies (NaPHOS), which together constitute the SIOPE Clinical Research Council. SIOP Europe has also established close cooperation with the parent, patient, and survivor advocates from Childhood Cancer International – Europe (CCI Europe) and the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare).

The progress made by SIOP Europe together with its partners and collaborators over the last 6 years has been highly visible. It is however timely to review in detail the progress against each of the planned objectives and cross-cutting platforms. It is essential to critically consider what has been achieved and, importantly, which of the SIOP Europe priorities are still relevant and thereby need to be re-set for the next 5 years in the context of the current clinical, societal and economic challenges for the paediatric oncology community.

Overall, substantial progress has been made against most but not all of the SIOP Europe Strategic Plan's objectives. Of note has been the impact of the **Oncopolicy agenda**, culminating in 2021 with the recognition of the needs of children and young people with cancer in a range of European Union (EU) initiatives. The collective and collaborative one voice approach with our partners has been pivotal in ensuring that the important messages on the needs of children and young people with cancer were heard at the level of the European Commission and the European Parliament. As a consequence, action has been taken and there is now a spotlight on children and young people, as evidenced in the 10th flagship initiative 'Helping Children with Cancer' within Europe's Beating Cancer Plan, the Horizon Europe Cancer Mission Board's 11th recommendation for intervention: 'Childhood cancers and cancers in adolescents and young adults: cure more and





cure better' and finally the Pharmaceutical Strategy for Europe opening the potential for legislative change within the Paediatric and Orphan Regulations to address their failure to deliver new therapies for children with cancer. The key challenge for the coming years will be to ensure the implementation of these strategies for the benefit of patients, their families and for survivors. SIOP Europe with CCI Europe is calling for the creation of the **EU Childhood Cancer Advisory Board** that would support the coordination of actions across all relevant EU initiatives, including among others, Europe's Beating Cancer Plan, the Horizon Europe Mission on Cancer, and the Pharmaceutical Strategy for Europe.

The establishment and subsequent activities of the **ACCELERATE** international multi-stakeholder platform represented an important milestone in identifying solutions to the barriers that have held back cancer drug development for children and young people.

Inequalities in many aspects of childhood cancer care continue across Europe but the foundation of the European Reference Network on Paediatric Cancer (**ERN PaedCan**) is a significant step towards addressing these inequalities. The close collaboration between SIOP Europe, ERN PaedCan, the European Clinical Trials Groups and CCI Europe has resulted in the **European Standard Clinical Practice (ESCP) Project**. This has generated clinical recommendations reflecting current best practice for a range of common childhood cancers and provide important benchmarks for the expected standard of care in Europe, to which all children and young people must have access.

Over the last 6 years, several **SIOP Europe Working Groups** have been established providing forums for driving progress against the strategic objectives. Notably, the SIOP Europe Radiation Oncology Working Group have delivered the **QUARTET project**, which is an important pan-European platform improving the quality of radiotherapy in clinical trials and provides a template for the development of future SIOP Europe quality assurance platforms for other aspects of the treatment pathway, for example diagnostic and interventional imaging.

The launch of the Young SIOPE Working Group focussed on our next generation has been a major success due to their enthusiasm and commitment. They have made substantial contributions to many SIOP Europe's projects, as exemplified in the **Access to Medicines Project** and the launch of an extensive **Education and Training Programme for European paediatric oncologists**. The new SIOP Europe endorsed training syllabus outlines the essential training requirements for trainees in paediatric haematology and oncology. SIOP Europe has launched a unique 2–3-year modular training programme, with a virtual meeting in March 2021 and plans for the first in-person annual course to be held in 2022. In addition, there are now a plethora of on-line webinars and podcasts delivered with our partners, including with the ERN PaedCan and the European School of Oncology (ESO).

SIOP Europe aims to bring together the whole spectrum of scientists, healthcare professionals, key opinion leaders and trainees interested in addressing the main challenges faced by childhood and adolescent oncology. The SIOP Europe **Annual Meeting** launched in 2019 has provided us with the much-needed platform for knowledge exchange and multi-disciplinary networking. This unique event included novel session formats, which are comparable to interactive workshops. The meeting hosted most of the European Clinical Trial Groups, thereby disseminating the outcomes of the high-quality clinical and basic research carried out in Europe. SIOP Europe is committed to strengthening the collaboration with patients, parents and survivors advocates and this was consolidated in the successful joining of the CCI Europe Annual Conference with the SIOP Europe Annual Meeting. Although cancelled in 2020 and pivoted to a virtual meeting in 2021 by the impact of the COVID-19 pandemic, we are hoping to return to an in-person meetings soon.

SIOP Europe, working together with the whole European paediatric oncology community, remains committed to achieving the ultimate goal of zero deaths and zero late complications for childhood and teenage cancer patients. A sustainable infrastructure throughout Europe for equal access to best practice in health care and research from diagnosis, through all modalities of treatment and through to long-term follow-up for survivors is our fundamental ambition. This Strategic Plan's 2021 updated objectives build on our collective experience and expertise and will leverage the implementation of the EU initiatives, including the childhood and adolescent focus within Europe's Beating Cancer Plan, the Horizon Europe Cancer Mission and the Pharmaceutical Strategy for Europe towards achieving our ambition: Cure All and Cure Better.





SIOP Europe Board Members to 2021

ELECTED BOARD MEMBERS (6)

Pamela Kearns, SIOP Europe President





Andishe Attarbaschi, SIOP Europe Board Member Education Lead

Stefan Bielack, SIOP Europe Board Member (2015-2020)

Tomasz Szczepański, SIOP Europe Board Member, Clinical Research Council NaPHOS Representative

> **François Doz**, SIOP Europe Board Member







BOARD MEMBERS APPOINTED BY BOARD (5)



Lars Hjorth, SIOP Europe Board Member



Ruth Ladenstein, SIOP Europe Board Member, ERN PaedCan Coordinator



Tom Boterberg, SIOP Europe Board Member



Reineke Schoot, SIOP Europe Board Member, Young SIOPE Chair



Gilles Vassal, SIOP Europe Board Member, Oncopolicy Lead





Progress on 2015-2020 Strategic Plan:

Seven Objectives 2015-2020



1. **Innovative treatments**: to introduce safe and effective innovative treatments (i.e. new drugs, new technologies) into standard care.

2. **Precision cancer medicine**: to use improved risk classification as well as biological characteristics of both the tumour and patient (such as molecular and immunological factors) to help guide decisions on which therapies to use.



3. **Tumour biology**: to increase knowledge of tumour biology and speed up translation from basic research to clinical care to benefit patients.



4. **Equal access**: to bring about equal access across Europe to standard care (in both diagnosis and treatment), expertise and clinical research.



5. **Teenagers and Young Adults**: to address the specific needs of teenagers and young adults (TYA), in cooperation with adult oncology.



6. Quality of survivorship: to address the consequences of cancer treatment such as long-term side effects, to better understand the genetic background/risk of an individual, and to improve quality of life of childhood cancer survivors.



7. **Causes of cancer**: to understand the causes of paediatric cancers and to address prevention wherever possible.



Objective 1: Innovative treatments

To introduce safe and effective innovative treatment (i.e. new drugs, new technologies) into standard of care.

The key aim of this objective is to increase the access of patients to new and innovative therapies across Europe, including better referral of patients, and install a molecular and immunological tumour profiling as a standard of care at the time of relapse as well as at diagnosis for patients with a high-risk and resistant diseases. Implementation was led by the European Consortium for Innovative Therapies for Children with Cancer (ITCC), in collaboration with the disease-specific European Clinical Trials Groups (ECTGs).

Summary of achievements (2015-2020)

Two initiatives have been delivered successfully towards promoting innovation in new therapeutics for the paediatric and adolescent cancer patient populations:



1. The **Joint Action on Rare Cancers** (JARC), a 3-year European project launched in October 2016 delivered a suite of policy recommendations on rare cancers that can be implemented by Member States and in relevant EU initiatives.

2. The ACCELERATE international multi-stakeholder platform was jointly created in 2015 by SIOP Europe, ITCC and CDDF within the ENCCA project (European Network for Cancer research in Children and Adolescents). A major output from this platform is the establishment of multi-stakeholder Paediatric Strategy Forums. Organised by the ACCELERATE international multi-stakeholder platform in a collaboration with the European Medicines Agency (EMA) and the US Food and Drug Administration (FDA), these forums define a strategy for new drug development in a given paediatric malignancy or a class of compounds with regards to their Mechanism of Action.

More information about those initiatives can be found in the chapter 'Facilitating platforms and cross-tumour programmes'.

In addition, SIOP Europe, together with CCI Europe and PanCare, has **influenced changes in the EU regulations** relevant to cancer drug development pathways for children and young people. SIOP Europe advocates important changes to the current European regulations and supports a regulatory environment that safely enables and promotes the development of new cancer drugs for children. All actions taken in this regard are detailed in the Oncopolicy Programme.



Objective 2: Precision cancer medicine

To use improved risk classification as well as biological characteristics of both the tumour and patient (such as molecular and immunological factors) to help guide decisions on which therapies to use.

The key aim of this objective is to analyse the specific biology (molecular profiling) of both the patient and tumour at the point of diagnosis and throughout treatment to improve risk stratification for adapted individual treatment by identifying a) patients with a high probability of cure with standard treatment, who may be proposed new or reduced interventions to decrease the risk of late complications and b) patients with a poor prognosis tumour to whom innovative therapies should be proposed as early as possible, to increase their probability of cure. Implementation again pivoted on the SIOPE European Clinical Trial Groups developing research in each paediatric malignancy with facilitation from SIOP Europe's cross-tumour European platforms and programmes.



Summary of achievements (2015-2020)

Establishment of national platforms for molecular stratification.

The Innovative Therapies for Children with Cancer (ITCC) Consortium introduced a 3-pillar strategy to generate big data that would help find new therapeutic targets. From 2015 to 2021, tumour exome and RNA sequencing data were collected from more than 3,000 patients with relapsed paediatric malignancies as part of Precision Oncology programmes run within the ITCC network. Data are being aggregated in a common asset to serve basic and translational research projects. The objective is to expand molecular tumour profiling and access to therapeutic innovation across Europe.

Expansion of the availability and accessibility of biomarkers for clinical and research use by setting up a network of the necessary molecular laboratories.

The progressive development of networks of the necessary molecular laboratories that expanded the availability and access of biomarkers for clinical and research use was reported by liquid tumour groups (in particular the I-BFM Study Group). Similar initiatives were planned by SIOPEN (SIOP Europe Neuroblastoma Group) and the SIOP Europe Brain Tumour Group.

Prospective clinical trials with innovative design and methods to confirm the use of biomarkers and algorithms in risk stratification, treatment allocation and disease monitoring.

Delivered by the European Clinical Trials Groups, several prospective clinical trials introducing the use of biomarkers in risk stratification and treatment allocation have been launched in the treatment of childhood cancers (e.g., for neuroblastoma in the SIOPENHRNBL2 trial, for acute lymphoblastic leukaemia in the I-BFM trials and for medulloblastoma in the SIOPE PNET 5MB trial).



Developing a European research platform for quality control in radiation therapy.

SIOP Europe launched the **QUARTET Project** to build a sustainable and prospective radiation oncology quality control platform. More information about this platform can be found in the '**Facilitating platforms and cross-tumour research projects**' section below.

Improving data sharing, especially those that are linked, such as genomic and clinical data, and widen access of such information to researchers.

Two projects were set up to meet the objective of data sharing and improving the access for research: the European Precision Cancer Medicine Programme (ITCC) and the PRIMAGE Project.

- The European Precision Oncology and New Drug Development programme, led by the ITCC since 2015 has generated complete sequencing information for more than 2,500 paediatric tumours biopsied at relapse through 5 studies. An ongoing project is developing the infrastructure to make these unique clinic-biological data accessible for basic and translational research projects.
- The PRIMAGE project implements the latest advancement of in-silico imaging biomarkers and modelling of tumour growth towards a personalised diagnosis, prognosis, and therapies follow-up.

In summary, this second objective (precision cancer medicine) was widely implemented by the European Clinical Trial Groups and multiple initiatives were undertaken at the national level. SIOP Europe, as an organisation, provided a platform for knowledge exchange and discussion for researchers and clinicians in Europe.





Objective 3: Tumour biology

To increase knowledge of tumour biology and speed up translation from basic research to clinical care to benefit patients.

The key aim of this objective is to use modern and innovative technologies to further uncover the mechanisms of paediatric tumour development, progression and relapse and to explore tumour genetic and cellular heterogeneity, (epi)-genetic and the role of the immune system, metabolism and the tumour micro-environment. In addition, an important aim is to accelerate the translation of results from research to clinical care and allow patients to benefit from new knowledge in a timely fashion.

Summary of achievements (2015-2020)

Measurement of the implementation and achievements against this objective is complicated by the nature of research delivery, which is often based on local or national expertise. Positive feedback has been received from international networks of basic research teams, working together aiming to increase the current knowledge on tumour biology. The crucial interactions between bio-informaticians, system biologists and developmental biologists have been maintained.

Towards identifying druggable targets in paediatric cancers and therefore accelerate the development of specific paediatric anti-cancer drugs, one major achievement was the establishment of **the Innovative Therapies for Children with Cancer Paediatric Preclinical Proof-of-concept Platform (ITCC-P4)**, a public-private partnership supported by the European consortium 'Innovative Medicines Initiative' (IMI). This initiative was launched in 2017 to establish 400 new patient-derived preclinical models of high-risk paediatric solid tumours, which will be fully characterised (molecularly, immunologically, pharmacologically and clinically well-annotated) and to build a sustainable comprehensive platform to use these models for drug testing.





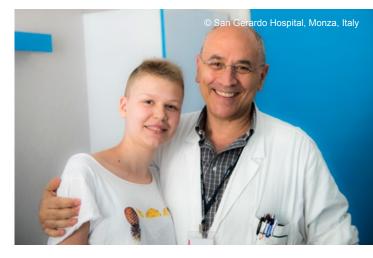
Objective 4: Equal access

To bring about equal access across Europe to standard care (in both diagnosis and treatment), expertise and clinical research.

The key aim of this objective is to ensure that all centres in Europe that treat children and TYA with cancer meet the European Standards of Care for Children with Cancer and to develop pathways that, for complex treatments and rare diseases/situations, allow access to specialised expertise, specialised technologies (i.e. specialised surgery, radiotherapy techniques, haematopoietic stem cell transplantation) or clinical research (i.e. early phase trials of new treatments).

Summary of achievements (2015-2020)

A major step towards reducing inequalities was achieved in 2017 with the creation of the European Reference Network on Paediatric Cancer (ERN PaedCan). The European Commission commissioned the establishment of **European Reference Networks (ERN)** in a range of rare diseases aiming to reduce the current inequalities in different EU Member States. The aim of the ERN PaedCan is to increase childhood cancer survival and quality of life by fostering cooperation, research and training with the ultimate goal to reduce current inequalities in childhood cancer survival and healthcare capabilities in different Member States. This was to be achieved through increased access to medical expertise and facilitation of information sharing beyond national borders. SIOP Europe is





European Reference Network

for rare or low prevalence complex diseases

Network Paediatric Cancer (ERN PaedCan)

working with ERN PaedCan to foster cooperation, research, training and knowledge sharing to end professional isolation, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities across Europe throughout each patient's cancer journey. This project is fully supported by SIOP Europe and the paediatric haemato-oncology community who is striving to make this important initiative work in the long term, for a future where all children and adolescents with cancer can be cured.

To ensure high-quality cross-border treatment for children and adolescents, ERN PaedCan is creating a common roadmap through interlinking cancer-specific sub-networks and creating transparency in the paediatric cancer healthcare arena by highlighting expert sites available for cross-border expert advice and patients' referrals.

A paediatric tumour board network is being implemented using the Clinical Patient Management System (CPMS) to optimise the accessibility of expert advice in the cross-border healthcare setting. The CPMS allows discussions amongst healthcare professionals across Europe. Medical healthcare professionals are able to receive advice on very rare cases and exchange knowledge with colleagues working in different countries. Low Health Expenditure Rate (LHEAR) country members are especially benefitting from this virtual exchange platform.

Furthermore, ERN PaedCan members together with the coordination by Vilnius University Hospital Santaros Klinikos (VULSK) developed the **TREL project** (Twinning in Research and Education to improve survival in Childhood Solid Tumours in Lithuania) aiming to enhance translational, clinical and late-effect research in paediatric solid tumours. Although twinning was hindered by the Covid-19 pandemic, e-learning activities could facilitate widening country experts to get the right training and education.





An important joint initiative of SIOP Europe and the ERN PaedCan called the **European Standard Clinical Practice** (**ESCP**) **Project** was launched in 2019 to develop and approve clinical recommendations reflecting current best practice for each common childhood cancer type. The ESCPs will be made available to all SIOP Europe and CCI Europe members on relevant websites. It is anticipated that the ESCPs protocols will provide important information to paediatric haemato-oncologists, patients, and families in situations where current standard best clinical practice is not available.

European standards concerning the organisation of care in paediatric haematology and oncology are being developed and updated in the SIOP Europe community and include the European Standards of Care for Children with Cancer (SIOP, 2009), the Recommendations on the Organisation of Care in Paediatric Radiation Oncology across Europe (Janssens, 2019), the PanCare/IGHG guidelines on childhood cancer survivorship and the EXPeRT guidelines on very rare tumours in the paediatric population.

SIOPE Access to Medicines Project

Two scientific projects were conducted to address issues regarding access to medicines for children with cancer in Europe.

The Essential Medicines Project was created to provide an updated evidence-based reference list of essential medicines for all paediatric cancer diseases to stakeholders in Europe, contribute to the next revision of the World Health Organization (WHO) Model Lists of Essential Medicines (2021) and initiate a dialogue with health technology assessment (HTA) bodies on evaluation of newly approved expensive anti-cancer medicines for children.

The project was launched in August 2019 and after over 20 months of work, the results were delivered. Coordinated by SIOP Europe and Young SIOPE, all European Clinical Trial Groups (ECTGs) contributed to a systematic evaluation of essential anticancer medicines for the treatment of children with cancer in Europe. In total, 21 mentors from the different ECTGs and 35 Young SIOPE members screened over 100 treatment protocols and defined a list of essential anti-cancer medicines. A selection of medicines was presented to the WHO Essential Medicines Committee and, in October 2021, 16 new medicines and indications were included under the updated WHO Essential Medicines List for Children 2021. During the project, the collaborations with the ERN PaedCan - SIOPE ESCP Project and the WHO were developed, with Young SIOPE members contributing to both projects and supporting the exchange of information.

A second project, conducted in collaboration with Young SIOPE and two Health Technology Assessment (HTA) experts, evaluated the process of HTA evaluations for a selection of anti-cancer medicines for children. This project was completed in September 2021 and a manuscript was submitted for publication in a peer-reviewed journal.



(N=16)

ACCESS TO





Objective 5: Teenagers and Young Adults

To address the specific needs of teenagers and young adults (TYA) (or Adolescents and Young Adults – AYA), in cooperation with adult oncology.

Although cancer in teenagers and young adults is rare, it is a substantial cause of death in this population. For some specific tumour types, outcomes are poorer than in younger patients with the same cancer, and several contributory factors have been identified such as the tumour's biology and sensitivity to current therapies, as well as the access to referral centres and the low participation of TYA in clinical trials.

TYA have specific and unmet needs, including complex psychological and social supportive care. Their position between adult and children's services in healthcare systems does not allow for the best possible provision of care or dedicated research that could improve their quality of survival.

The aim is to develop a comprehensive multidisciplinary European programme, tackling all issues and specific needs of the TYA population. This will be a joint integrated programme between paediatric and adult oncology, in strong partnership with patients.

Summary of achievements (2015-2020)



In 2016, SIOPE and ESMO created the joint **Working Group on Cancer in Adolescents and Young Adults (AYA)** to promote education in cancer topics specific to this population. The Group's aims are to increase awareness amongst the medical and paediatric oncology communities and enhance knowledge on specific cancer issues in AYA. The group also advocates for an increase in research capacities in tumour types affecting these patients and cultivating sensitive collaborative relations between medical and paediatric oncologists, as well as with other healthcare professionals involved in AYA care. The group successfully organised joint sessions during the ESMO Conferences and the SIOP Europe Annual Meeting. In addition, this Group has conducted research based on a survey, provided AYA e-learning modules and an AYA Preceptorship Programme for Adolescents & Young Adults Malignancies.

The **SIOP Europe AYA Committee** was launched on the occasion of the SIOP Europe Annual Meeting on 20-24 May 2019 in Prague, Czech Republic. The AYA Committee aims to provide and receive strategic and direction-forming input into and from existing networks and groups such as the European Network for Teenagers and Young Adults with Cancer (ENTYAC) and the ESMO/SIOP Europe AYA Working Group,

other SIOPE Working Groups, as well as to liaise with professional and patient organisations to bring AYA issues onto the political agenda.

In order to address the specific needs of adolescents and young adults, SIOP Europe collaborated with the European Society of Gynaecological Oncology (ESGO) on the creation of clinically relevant and evidence-based guidelines for the management of non-epithelial ovarian cancers, including malignant ovarian germ cell tumours, sex cord-stromal tumours, and small cell carcinoma of the ovary of hypercalcaemic type in adolescents and young adults. The guidelines were published in The Lancet Oncology in July 2020.

Building on the success of this collaboration, SIOPE Europe has joined with ESGO and ESTRO to develop a set of guidelines for the management of patients with vaginal cancer to be published in 2022.

All of these initiatives together aim to bring adult oncology, paediatric oncology, haematology, nursing, social work clinical communities and patient organisations together across Europe.



PROGRESS ON 2015-2020 STRATEGIC PLAN SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)



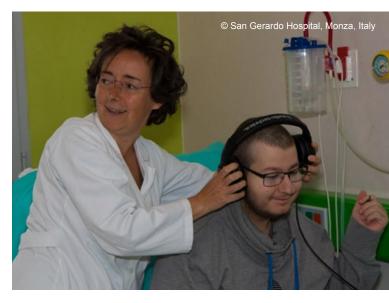
Objective 6: Quality of survivorship

Quality of survivorship: to address the consequences of cancer treatment including long-term complications, to better understand the genetic background/risk of an individual, and to ultimately improve quality of life of survivors of childhood cancer.

With an 80% survival at five years, the number of childhood cancer survivors (currently more than 300,000 in Europe) will continue to increase. Improving their quality of life is a major and crucial goal. At least two-thirds of survivors have early-or late-occurring complications due to their treatments, which are severe or even life-threatening for 25% of survivors. This has a strong impact on survivors' daily lives as well as their families. By 2030, it is anticipated that there will be around 750,000 paediatric cancer survivors in Europe.

Summary of achievements (2015-2020)

The PanCare network was created in 2008 to address this issue. PanCare, a pan-European multidisciplinary network of health professionals, survivors of paediatric cancer and their families, seeks to reduce the frequency, severity and



impact of late complications of treatment. This network aims to ensure that every childhood cancer survivor receives the best possible long-term care. In addition, several survivors' associations were recently created to empower survivors and to help them tackle the issues they face.

Two FP7 European projects, PanCareSurFup (2011-2017) and PanCareLIFE (2013-2018), carried out research on lateoccurring complications. The pilot initiative of the 'Survivorship Passport' was developed with the support of the ENCCA project and PanCareSurFup, and the organisation of care including a virtual late complications advisory centre addressed within the pilot reference network ExPO-r-NET project.

The Survivorship Passport was launched and implemented in Italy on 13 February 2018. All 53 AIEOP centres in Italy can use the Survivorship Passport for their patients after the end of treatment.

CCI Europe, PanCare and SIOP Europe have committed to establishing a long-term sustainable strategy for future cooperation on survivorship care, working together to assess the needs of childhood and adolescent cancer survivors and together identify potential opportunities to address these needs. CCI Europe, PanCare and SIOP Europe signed a Memorandum of Understanding (MoU) in February 2019. The goal of this MoU is to establish a long-term sustainable strategy for future cooperation on survivorship care. The partners plan to work together to assess the needs of childhood and adolescent cancer survivors and to collaborate to identify potential opportunities to address these needs. One such opportunity is the continued development and implementation of the **Survivorship Passport**.

A new ongoing European project in Horizon 2020, PanCareFollowUp (2019-2023), has continued the work from PanCareSurFup and PanCareLIFE in securing guidelines for long-term follow-up of childhood cancer survivors. As part of the project, a full suite of recommendation guidelines was developed: 12 guidelines were developed by the IGHG group in collaboration with PanCareSurFup, PanCareLIFE and PanCare and 33 recommendations were developed within the PanCareFollowUp project. Within the project scope, these guidelines will be translated into plain language and made available to parents and patients.





Objective 7: Causes of cancer

To understand the causes of paediatric cancers and to address prevention wherever possible.

Relatively few causative factors have been identified so far for childhood cancers. It is estimated that 4-8% of paediatric cancers occur within a known genetic predisposition and more than 100 genetic syndromes with a risk of cancer in childhood are known. The proportion may increase as more and more rare cancer gene mutations are discovered through ongoing analyses in areas such as genomics.

The key aim is to increase research focused on predisposition to childhood cancer and on the oncogenic drivers that increase the risk of childhood cancer by:

- → Using whole genome sequencing to further uncover genetic predisposition to paediatric cancers.
- Addressing the pragmatic and ethical issues of genetic testing and counselling, anticipating that DNA testing is becoming widely available.
- Addressing questions on the environmental causes of paediatric cancer through scientifically led and evidencebased studies.

Summary of achievements (2015-2020)

Identifying children with cancer predisposition syndromes (CPS) has significant clinical consequences for the patient and their family. Recent advances in genetics have led to better understanding and early detection of these syndromes and offer the potential for preclinical diagnosis. The challenge faced by most paediatric oncologists is navigating these complexities to identify at-risk children, who will benefit from genetic testing and counselling. The SIOPE Host Genome Working Group (HGWG) was officially launched during the first SIOP Europe Annual Meeting in Prague 2019 with the aim to study and broaden the expertise in this field. In spite of being a relatively new Working Group, its members have been very active and the progress of the HGWG is summarised in their contribution to several important publications in this field including (but not limited to):



- Kratz CP, Jongmans MC, Cavé H, Wimmer K, Behjati S, Guerrini-Rousseau L, Milde T, Pajtler KW, Golmard L, Gauthier-Villars M, Jewell R, Duncan C, Maher ER, Brugieres L, Pritchard-Jones K, Bourdeaut F. Predisposition to cancer in children and adolescents. Lancet Child Adolesc Health. 2021 Feb;5(2):142-154.
- Byrjalsen A, Diets IJ, Bakhuizen J, Hansen TVO, Schmiegelow K, Gerdes AM, Stoltze U, Kuiper RP, Merks JHM, Wadt K, Jongmans M. Selection criteria for assembling a pediatric cancer predisposition syndrome gene panel. Fam Cancer. 2021 Jun 1.
- Guerrini-Rousseau L, Smith MJ, Kratz CP, Doergeloh B, Hirsch S, Hopman SMJ, Jorgensen M, Kuhlen M, Michaeli O, Milde T, Ridola V, Russo A, Salvador H, Waespe N, Claret B, Brugieres L, Evans DG. Current recommendations for cancer surveillance in Gorlin syndrome: a report from the SIOPE host genome working group (SIOPE HGWG). Fam Cancer. 2021 Apr 16. doi: 10.1007/s10689-021-00247-z. Epub ahead of print. PMID: 33860896.



Facilitating platforms and cross-tumour programmes

While delivering the SIOP Europe Strategic Objectives, the need for a number of facilitating Platforms and Cross-Tumour Programmes was identified and here we report on the progress of these initiatives:

Clinical Trials Facilitation

A platform to facilitate the setup of clinical trials within the new EU Clinical Trial Regulation.

The Clinical Trial Facilitation (CTF) platform was an initiative to facilitate the anticipated transition from the EU Clinical Trial Directive to the Clinical Trial Regulation that would allow researchers to share their experiences and solutions to issues related to the Regulation's implementation. The way clinical trials are conducted in the European Union (EU) will undergo a major change when the Clinical Trial Regulation (Regulation (EU) No 536/2014) is implemented, but this was unexpectedly delayed due to technical difficulties with the development of the IT systems and the Regulation will now only be implemented on 31 January 2022.

Summary of achievements (2015-2020)

SIOP Europe Clinical Trial Protocols and Contract templates

In 2016, SIOP Europe sent out a questionnaire to 19 European Clinical Trial Groups to assess the needs of the community and facilitate the transition to the Clinical Trial Regulation. The Groups were asked to rate the needs of the clinical trial community on a scale: 0-5 [where 0 = 'of no interest and/or benefit' and 5 = 'of critical interest and/or benefit']. Sixteen Groups provided their feedback and as a consequence of this survey, it was possible to establish the main needs of the paediatric clinical trial community in Europe and map the framework for a toolkit to include guidance documents and templates.

The top 4 areas identified as those of greatest need were:

- Template for Sponsor- Co-sponsor/National coordinating centre agreements defining delegated duties and responsibilities.
- Clinical Trial Protocol Template.
- → Guidance for trial management and monitoring, including how to manage serious breaches in trial compliance.
- Guidance on clinical trial risk assessment as defined in the forthcoming EU Clinical Trial Regulation (CTR).

To facilitate investigators in the delivery of international clinical trials in paediatric oncology, where needed, SIOP Europe developed a clinical trial protocol template (a deliverable achieved as part of ENCCA) and a template for a contract between sponsors and national coordinating centres. Both templates are available for use and can be downloaded from the SIOP Europe website.

Upon the implementation of the CTR, SIOP Europe will work with the Clinical Trial Groups on guidance on its application in the context of paediatric oncology clinical trials, notably the risk assessment and the management trial oversight and protocol compliance.





PICORET

The PICORET Project is the clinical epidemiology platform for outcome research.

The Population Improvement in Childhood Cancer Outcomes through Research, Evaluation and Training project (PICORET) aims to address the needs of clinical epidemiology and outcome research in paediatric haemato-oncology.

PICORET consequently monitors the survival of all children and adolescents with cancer in Europe and evaluate progress across Europe using information from registries and observational studies that use standard treatments.

Such 'non-interventional' clinical studies can assess the effectiveness of biomarkers, which can be used for prognosis, and allow the analysis of traditionally hard-to-research areas, such as surgical and imaging techniques.

Several paediatric cancers have a high survival rate with treatments that have been established through prospective European randomised trials. Population-based cancer registries measure overall but not relapse-free survival, and so there is not sufficient information on the effectiveness of first-line therapy at a population level.

Summary of achievements (2015-2020)

The PICORET Project was partially integrated into the **JARC** (the JARC Work Package on 'Epidemiology'), including some of the identified paediatric oncology needs, which was previously submitted by SIOP Europe partners to the European Commission as a potential Horizon 2020 project.

In addition, one of the aims to use information from European registries and observational studies to monitor and evaluate progress in the survival of children and adolescents treated for cancer is aligned to the **ERN PaedCan** objectives and is therefore now incorporated into the activities of the ERN PaedCan.







QUARTET Project

Quality and Excellence in Radiotherapy and Imaging for Children and Adolescents with Cancer across Europe in Clinical Trials (QUARTET).

The **QUARTET Project** (Quality and Excellence in Radiotherapy and Imaging for Children and Adolescents with Cancer across Europe in Clinical Trials) is a centralised, prospective quality assurance programme standardising radiotherapy and imaging in international paediatric trials. This collaboration between SIOP Europe and the EORTC has been realised with the financial support of the Luxembourg Foundatioun Kriibskrank Kanner.



Establishing the effectiveness of the use of radiotherapy plays an important role in achieving better outcomes for childhood cancers patients. The ultimate ambition of the QUARTET project is to increase cure rates for children with cancer and reduce long-term treatment-related side effects, by establishing quality assurance standards in paediatric radiotherapy and imaging and ensuring equitable access to high-quality treatment. The project also aims to develop research on the role of Quality Assurance in radiotherapy, including improving understanding of the specific normal tissue tolerances for children and adolescents.

QUARTET will meet this goal through the implementation of a prospective radiotherapy quality assurance (RTQA) programme in clinical trials for a range of childhood and adolescent cancers. The project should be considered across all childhood cancer types, including rare diseases where shared expertise may be of particular advantage.

By guaranteeing that all children have access to high-quality radiotherapy that balances tumour control and quality of life, regardless of where in Europe they may be treated, the QUARTET Project is an important component of the SIOP Europe Strategic Plan.

Summary of achievements (2015-2020)



The QUARTET project has approved eight clinical trials for prospective RTQA, with two more on the horizon, one retrospective radiotherapy quality analysis, three prospective imaging studies and one retrospective imaging study.

Comprehensive guidelines that present the trial requirements for planning and delivery and supported by best practice publications wherever available have been developed and are approved by the trial sponsors and have been circulated to all participating sites for the overarching study for children and adults with <u>F</u>rontline <u>and Relapsed rhabdomyosarcoma</u> (FaR-RMS) and High-risk Neuroblastoma-2 (HR-NBL2) trials. RTQA site approvals for both trials are well under way and will be ready to further open to recruitment later this year in 2021. RTQA guidelines are also in development for several other trials and will be finalised also within 2021. Review processes and the supporting infrastructure have all been set in place.

SIOP Europe, EORTC, and QUARTET have collaborated with trial sponsors to guarantee that all legal and administrative frameworks are in place to ensure the success of QUARTET.

QUARTET also collaborated with the Global Quality Assurance of Radiation Therapy Clinical Trials Harmonisation Group (Global Harmonisation Group, GHG), which is a collaborative group of RTQA organisations from around the world. The GHG believes that harmonisation of RTQA across the groups will help support high-quality radiotherapy delivery in clinical trials and therefore reduce ambiguities in trial reporting and analysis.





Multi-stakeholder platform for new paediatric oncology drug development



The establishment of **ACCELERATE** met the standards of this unique international multi-stakeholder platform providing a transparent forum to discuss and address overarching issues to accelerate innovation in drug development for children and adolescents with cancer. In 2015, the ACCELERATE Platform was created by SIOP Europe and ITCC (Innovative Therapies for Children with Cancer Consortium) with a very simple and basic principle: bringing all stakeholders to work together to share a common understanding of the issues, to identify hurdles and barriers, to propose solutions and monitor their implementation. In 2021, more than 300 people from 26 countries worldwide participated in this initiative. This multi-stakeholder platform includes patients' and parents' organisations, academic paediatric oncologists and haematologists and academic researchers, the pharmaceutical industry and regulatory bodies.

The overarching objectives are:

- Accelerating science-driven development of paediatric oncology drugs based on mechanism-of-action rather than adult indication.
- Facilitating international cooperation and collaboration among stakeholders.
- Improving early access to new anti-cancer drugs in development for children and adolescents.
- Setting up long-term follow-up of children and adolescents exposed to new drugs.

Summary of achievements (2015-2020)

Facilitate prioritisation through Paediatric Strategy Forums

Paediatric Strategy Forums have been created to evaluate science, facilitate dialogue, and provide an opportunity for constructive interactions between relevant stakeholders (patient advocates, clinicians, academics, biotechnology/ pharmaceutical companies and regulators) on specific topics requiring open discussion on the development of medicines in the best interests of children and adolescents with cancer. The objective is to define the unmet medical needs of children with cancer and to facilitate prioritisation and set up a strategy for the development of anti-cancer compounds to address those needs.

Since 2017, seven Paediatric Strategy Forums have been held in partnership with the European Medicines Agency with the participation of the Food and Drug Administration.



PROGRESS ON 2015-2020 STRATEGIC PLAN SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)



Sharing, brainstorming and identifying issues

The ACCELERATE Paediatric Oncology Conference takes place every year in Brussels, Belgium. It offers presentations from a spectrum of international experts on clinical and preclinical paediatric oncology research, regulatory challenges worldwide, patient and parent advocate activities and priorities. Yearly, the Annual Conference is set up as a working meeting with all stakeholders. Discussion and engagement opportunities are promoted, participants contribute to developing annual Work Programmes and hear reports of the organisation's achievements.

Deliver solutions through Working Groups

Seven Working Groups have been established since the creation of ACCELERATE. On given topics chosen during the Annual Conference, ACCELERATE explores the current situation, identifies bottlenecks, and hurdles and makes proposals to improve the development of anticancer drugs in the paediatric and adolescent population explored further by the Working Groups.

In its pilot phase, a working group on new development strategies has established the needs for drug mechanism-ofaction driven paediatric development plans (instead of adult-indication driven plans), access to a large clinic-biological database on paediatric tumours, more preclinical evaluation on relevant models and the implantation of the Paediatric Strategy Forum to facilitate prioritisation of medicinal products. The Fostering Age Inclusive Research (FAIR) group promotes the inclusion of adolescents in trials for adults when scientifically and medically justified. ACCELERATE has set up a process to label such industry and academic trials with the FAIR to AYA stamp.







Cross-Tumour Programmes

Oncopolicy Programme

The goal was to facilitate the development of the European environment needed to achieve the overarching SIOP Europe goals and to warrant that EU regulatory initiatives and programmes adequately address the needs of children and adolescents with cancer.

Summary of achievements (2015-2020)

- → Consolidated the position and visibility of SIOP Europe as the organisation of reference on policy issues pertaining to childhood cancers among EU stakeholders.
- Undertook a comprehensive campaign in collaboration with parents on the EU Paediatric Regulation, with messages supported by the European Parliament in an official Resolution and reflected in the European Commission evaluation report of the Regulation.
- Successfully led a dedicated Work Package on Paediatric Cancer in the EU Joint Action on Rare Cancers (2016-2019), producing evidence-based policy recommendations on access to essential medicines and radiation oncology, access to innovation, survivorship and very rare tumours.
- Produced and widely disseminated a number of impactful Oncopolicy publications (see <u>Annex</u>).

Each year, a unique event is organised in the European Parliament (EP) on the occasion of the International Childhood Cancer Day (ICCD) in February to discuss childhood cancer topics, often in relation to the EP's legislative agenda, with Members of the European Parliament (MEPs) and members of the childhood cancer community. In addition, SIOP Europe is organising regular events with the MEPs Against Cancer (MAC) Interest Group. Over the last 2 years, there has been an extraordinary mobilisation against cancer in Europe, especially with the launch of the Horizon Europe Cancer Mission and Europe's Beating Cancer Plan. SIOP Europe had the opportunity to set up bilateral meetings with high-level EU decision-makers and gain the support of several political groups in the EP. Childhood cancers are now under the spotlight at the EU level.

Gold Ribbon Campaign

The Gold Ribbon is the universal symbol to create awareness about childhood cancer. Since September 2019, SIOP Europe has been actively involving policy makers in the Gold Ribbon Campaign. As a result, more than 40 MEPs from 18 countries showed their support of the paediatric cancer cause by wearing the Gold Ribbon pin and sharing their engagement on social media.

European Elections 2019 Manifesto

Every 5 years, EU citizens elect MEPs from their country to represent them in EU policymaking. This is an opportunity to encourage candidates to sustain and reinforce the support of the paediatric cancer cause by means of a European Elections Manifesto.

The SIOP Europe and CCI Europe Manifesto for the European Elections 2019 was entitled 'Beating childhood cancer: Cure more and cure better - Towards zero deaths and zero late effects'. This Manifesto was launched at the ICCD event at the European Parliament on 6 March 2019. The MAC President and other leading MEPs took part and 27 MEPs from 18 countries signed the Manifesto.

BEATING CHILDHOOD CANCER-CURE MORE AND CURE BETTER TOWARDS ZERO DEATHS AND ZERO LATE EFFECTS ean Elections 2019 Manifesto for the







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Paediatric Regulation Campaign

The aim of the EU Paediatric Regulation (2006) was to foster the development of medicines for children. However, despite success in other disease areas, it has not been able to appropriately address the needs in paediatric cancer. In 2016, the European Commission published its 10-year report on its evaluation of the Regulation, which confirmed the concern that paediatric oncology had not been well served by the Regulation.

SIOP Europe has been working with multiple stakeholders as part of ACCELERATE to identify loopholes and implement improvement solutions. As of 2015, an extensive campaign on the Paediatric Regulation was undertaken in cooperation with parents.

In December 2016, the European Parliament voted for a Resolution on Paediatric Medicines calling for a change in the Regulation.

In 2017, The European Commission issued a report to the European Parliament and the Council on recognising the issues but not proposing changes. In 2018, the European Commission and the European Medicine Agency (EMA) released a plan of action to improve the implementation of the Regulation. Its implementation was delayed due to the move of the EMA to Amsterdam after Brexit and, subsequently, due to the COVID-19 pandemic.

In 2020, the European Commission released a report on the joint evaluation of the Paediatric and Orphan Medicines regulations highlighting that "the greatest therapeutic needs of children (such as treatments of children's cancers and for new-borns) have not been addressed". In addition, neither regulation has proven effective in boosting the development of innovative medicines for children with rare diseases, such as childhood cancer.

In 2021, the preparation of a revision of the Paediatric and Orphan medicines regulations is ongoing as part of the new EU Pharmaceutical Strategy. SIOP Europe is actively working together with CCI Europe and PanCare to contribute to this regulatory initiative, which is likely to improve the development of innovative medicines for children with cancer in the future.

Joint Action on Rare Cancers (JARC)

The Joint Action on Rare Cancers (JARC) was a 3-year initiative launched jointly by the European Commission and Member States with the aim to formulate policy recommendations on rare cancers. It concluded in September 2019 with the publication of the Rare Cancer Agenda 2030: Ten Policy Recommendations.



SIOP Europe was nominated to lead JARC Work Package 9 on Childhood Cancers and contributed across other work streams, working in partnership with CCI Europe and PanCare.

The JARC was an important opportunity to advance some of the key objectives of the SIOPE Strategic Plan.

National Cancer Control Programmes (NCCPs)

National cancer planning is an important policy tool linking the national with the EU level. The recommendation on ensuring a comprehensive paediatric cancer section in each NCCP has become an integral part of the JARC recommendations and placed the SIOPE Strategic Plan at the centre:

S6 "NCCPs should include a clearly designated section on paediatric cancers and integrate specific provisions concerning at least the following areas: epidemiology; healthcare organisation and quality; access to the best possible multimodal standard treatment; clinical research and access to innovative therapies; access to social needs of patients and families; survivorship." Ref: JARC –Rare Cancer Agenda 2030: Ten Recommendations.

In addition, SIOP Europe contributed to a JARC publication on rare and paediatric cancers in the NCCPs of 15 EU Member States, which served as a valuable evidence-generating activity for further advocacy.





ERN PaedCan and Cross-Border Healthcare Directive

The European Reference Networks were among the primary focus areas of the JARC. The initiative enabled SIOP Europe to put forward concrete recommendations to support the ERN PaedCan and streamline the implementation of the Cross-Border Healthcare Directive:

- → Allocation of non-competitive EU funding across the ERN PaedCan activities.
- Cross-border care reimbursement predictability to avoid unnecessary burden on families and inclusion of potentially life-saving clinical trials in the scope of the provisions.

Beyond the JARC, the ERN PaedCan is an integral part of all SIOP Europe policy initiatives. In addition, SIOP Europe contributed to a series of EU consultations in 2021 on the Evaluation of patient rights in cross-border healthcare.

Progress on other policy initiatives

General Data Protection Regulation (GPDR)

SIOPE was at the forefront of the GDPR negotiation process between the European Commission, the European Parliament, and the Council of the EU to ensure that the provisions were aligned with a thriving cross-border health research environment. A landmark event was organised by SIOPE on the occasion of the ICCD 2015 – 'Balancing Personal Data Protection and Research Progress: The Case of Childhood Cancer'.

SIOP Europe also joined forces with ESMO and other stakeholders in a position paper on the GDPR, calling to secure one-time withdrawable consent for retrospective research and enabling population-based registration.

The EU General Data Protection Regulation 2016/679 came into force on May 25, 2018.

At present, the priority is further advocacy towards Member States to foster a harmonious implementation and interpretation of the GDPR on health research clauses.





Education & training

SIOP Europe's Educational Programme aims to work towards the overarching goal of equal access to the best-possible standards of care by providing high-quality training for all healthcare professionals caring for children and adolescents with cancer across Europe.

SIOP Europe strives to make paediatric oncology a recognised sub-speciality in paediatric medicine across Europe, by giving paediatricians the expertise in clinical and basic research in paediatric oncology as well as in all different aspects of dealing with cancer in children and adolescents.

SIOP Europe's training and education programme encourages high-quality clinical and basic research as well as the delivery of high-quality care in paediatric oncology throughout Europe, focusing on the organisation of educational courses, E-learning programmes such as webinars, extensive exchange with Young SIOPE and providing a training syllabus in paediatric oncology.



Summary of achievements (2015-2020)

SIOP Europe has been involved in several training courses to develop the knowledge of healthcare professionals on new and state-of-the-art therapies and to allow them to gain more practical skills in the diagnosis and treatment of paediatric malignancies. SIOP Europe has recently launched a new SIOP Europe Course in Paediatric Oncology, as well as a fully updated European Training Programme in Paediatric Haematology and Oncology (Syllabus).

The **European Training Programme in Paediatric Haematology and Oncology** (Syllabus) is a comprehensive document detailing the SIOP Europe endorsed training programme that provides the recommended essential training requirements for trainees in paediatric haematology and oncology to be delivered in a 2-year modular training programme with an optional third year possible.

SIOP Europe has been involved in joint educational activities, such as the Workshop on Methods in Clinical Cancer Research (MCCR), SIOPE-ESMO e-Learning in Cancer in Adolescents and Young Adults, ESO-SIOPE e-Learning in Paediatric Oncology, ESO-SIOPE Clinical Training Centres – Paediatric Fellowship Programme and the ESO-SIOPE Masterclass in Paediatric Oncology.

SIOP Europe Course in Paediatric Oncology



This Course aims to provide training opportunities to physicians throughout Europe, to become leading physicians equipped with skills and ideas for high-quality patient management, clinical paediatric oncology research and the tools and resources to make their ideas become a reality. Focused on patient cases, three annual modules (CME certified) will be delivered, each lasting 4 days, with a maximum of 50 participants.

The kick-off meeting took place in March 2021 and the first module of the course will take place in April 2022.





ESO-SIOPE Masterclass



The ESO-SIOPE Masterclass in Paediatric Oncology is a CME-accredited clinically-oriented educational programme, which has been designed to offer a unique learning experience.

The 8th edition of this course took place online on 27 November – 2 December 2021.

ESO-SIOPE Clinical Training Centres – Paediatric Fellowship Programme

ESO and SIOP Europe have collaborated on a joint fellowship programme for young paediatric haematologists and oncologists aiming to gain clinical experience at renowned centres across Europe.

ESO-SIOPE E-Learning in Paediatric Oncology

SIOP Europe teamed up with ESO to expand the paediatric oncology content available via e-Learning modules.

Two pathways have been developed: Paediatric Haemato-Oncology Emergencies, with a total of eight e-learning sessions and Paediatric Oncology with nine sessions, all available on demand.

Online webinars



ERN PaedCan and Young SIOPE interactive webinar series – Monthly webinars were organised in a collaboration between ERN PaedCan, Young SIOPE and the SIOP Europe office, with a discussion of difficult clinical cases. Cases were presented by a junior (Young SIOPE) member and an expert from the field.

Young SIOPE – Young COG webinar series – In collaboration with the North American Young COG committee, a series of educational webinars was organised. Invited experts were asked to discuss hot topics, followed by a discussion moderated by Young SIOPE members.



SIOP Europe communication & IT portal

This "one-stop-shop" communication aims to facilitate information exchange and interaction between everyone involved in implementing the SIOP Europe strategic agenda.

The efforts and energy resulting from an active membership are compelling. SIOPE aspires to drive substantial positive transformation across the paediatric oncology landscape in Europe.

Authentic open dialogue is essential to any organisation and effective communication builds strong relationships. Trust is a key factor in any relationship and is enhanced by communication that is focused on meeting the needs of SIOP Europe's various stakeholders, conveying relevant and important information and facilitating a two-way dialogue.

SIOP Europe has the opportunity to foster a dynamic, engaged and connected professional community by:

- Engaging members and expanding its reach in the medical community and European policy level on various issues.
- Utilising numerous opportunities for engagement through multiple channels to help promote a vibrant healthcare professional community.
- Systematically exploring other and new engagement formats going forward depending on emerging needs.

SIOP Europe's communication initiatives and activities are planned to achieve results over three different time frames:

- Short-term: Focus is on issue-/event-driven communications and follow-through with existing processes (i.e. direct emailing/newsletters, media, including press releases, social media campaigns, etc.). The success of short-term communication depends on high quality and timely flow of communication. Good stakeholder relationships are an important component of this style of activity.
- Mid-term: Focus is on initiatives-based proactive communications reflecting SIOP Europe's role as a European association (i.e., regular review of current communications tools including publications, signage/roll-up posters, websites, advertising); development of new and review of existing communications approaches and materials for promotional/special events).



Long-term: Development of new (if so required) or review of the existing overarching communications plan, creation of sub-plans by activity and/or events, establishing priorities/tactics and developing appropriate timelines. This process is undertaken every three years.

Summary of achievements (2015-2020)

A major achievement was the launch of the **SIOP Europe Annual Meeting**. This was an ambitious initiative that aimed to provide the European paediatric oncology community with a unique cross-disciplinary networking event. Different from the majority of the scientific meetings, the SIOP Europe Annual Meeting was created as a joint working meeting of different European Clinical Trials Groups, Young Oncologists and Parent & Survivor representatives.



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The scientific programme of the Virtual Annual Meeting focuses on cross-tumour topics and joint sessions between two or more Groups, enabling direct interactions between tumour and clinical trial groups, parent groups, and survivors.



In partnership with CCI Europe, it was launched successfully in 2019 with the inaugural meeting in Prague.

This first SIOP Europe Annual Meeting surpassed expectations in terms of attendance with over 1,400 participants from 65 countries. Besides the closed sessions and meetings, the programme included: 22 Working Groups, 20 Joint Sessions and 11 Plenary Sessions.

The Plenary Sessions on Wednesday 22 May 2019 consisted of multi-stakeholder discussions on important cross-tumour topics and best practice as well as discussions on how SIOP Europe is delivering on its Strategic Plan for children and young people with cancer; presentations on ERN PaedCan; Joint Action on Rare Cancers (JARC) Essential Medicines; recommendations for the organisation of care in paediatric radiation oncology across Europe; and how SIOP Europe is influencing Oncopolicy.

Furthermore, 4 specific working groups were officially presented and launched at this Annual Meeting:

- Young SIOPE
- SIOP Europe Radiation Oncology Working Group
- SIOP Europe AYA Committee
- SIOP Europe Host Genome Working Group









Our plans for the second edition of the SIOPE Annual Meeting were interrupted in 2020 by the global impact of the COVID-19 pandemic but a rather different version of the meeting returned in 2021 as we hosted a virtual event, that surpassed our expectations.



The virtual edition attracted 1,558 participants from 65 countries and included 287 speakers and 73 sessions. On average, each session was joined by 170 participants live (up to 546) and more than 90 participants have watched the recording of each session (up to 224 views for the most popular recordings). All pre-recorded educational sessions were viewed 1,790 times in total.

During this 3-Day Virtual SIOP Europe Annual Meeting, 47 Live Sessions (including 23 Joint Sessions), 27 Operational Meetings (closed or semi-open), 6 On Demand Educational Sessions and 3 Industry Symposia were held.

Judging by the number of participants, the quality of the exchanges and discussions as well as the feedback received thus far, SIOP Europe is delighted that a pandemic did not stop science and this gathering of our community.

Given the importance of advocacy to our core activity, SIOP Europe has focused heavily on involving the highly engaged medical professionals in further developing the concerted dialogue at the EU level.

Our message was delivered via multiple communication routes including:

- Positioning and promoting the vision: Continuously repeat the vision in publications, statements, events, visual presentations, digital communication tools, etc.
- Positive News: Amplify the communication value of activities/initiatives that support SIOP Europe's vision. Promote these using integrated marketing strategies (media, articles/editorials, videos, publications, social media).
- Speaking to relevant stakeholders: Aim to capitalise on opportunities to explain SIOP EUROPE's vision and progress being made in achieving the objectives by encouraging senior management/board members to engage with the various stakeholders.
- Website: This is a key channel that is used to disseminate relevant information, receive inquiries, promote achievements and progress, raise donation efforts. This is a constantly growing communication tool and its use will be further developed especially during times of crisis (i.e. pandemic).
- Community development: Employees support and participate in ongoing community initiatives to promote health. The SIOP Europe Run took place in 2018 and 2019. This is also an opportunity for fundraising and advocating for health.



Future Perspective and Strategic Objectives for 2021-2026

The Paediatric Oncology community, working with multiple and diverse stakeholders has made substantial progress towards the SIOP Europe 2015-2020 Objectives, but much more remains to be achieved towards our mission to ensure the best possible care and outcome for all children and adolescents with cancer in Europe. In the next 5 years, we need to build on our achievements to date and exploit the new opportunities in research technologies, notably in the arena of data science, machine learning and Artificial Intelligence (AI). We are entering an exciting era for oncopolicy and advocacy in Europe, with cancer, and specifically cancer in children and young people stepping into the spotlight. We need to capitalise on the opportunities arising from Europe's Beating Cancer Plan and the associated potential Horizon Europe and EU4Health funding streams to support the delivery of our objectives and achieve our goal of zero deaths and zero side effects for our patients.

A principal aim over the next 5 years is to address inequalities for children and young people with cancer across Europe throughout their cancer journey, from diagnosis, through treatment and long-term follow-up, as well as where needed palliative care. To achieve this, the 7 objectives identified for 2015-2020 are still valid but are restructured to align with the current and evolving clinical and research infrastructures for childhood and adolescent cancers and the deliverables for the next 5 years are updated. We add an additional objective to develop the infrastructure to implement Big Data and Artificial Intelligence research and innovation for the benefit of children and young people with cancer.











1. Addressing Inequalities: to bring about equal access to standard care, expertise and clinical research for diagnosis, treatment and follow-up across Europe and to promote patient involvement and a patient-centred approach throughout.

2. **Precision Medicine and Treatment innovation:** development of new, safer and more effective therapies and improved multi-factor risk classification (including molecular and immunological factors) to help guide decisions on which therapies to use.



3. **Tumour Biology**: to foster increased knowledge of tumour biology and speed up translation from basic research to clinical care to benefit patients.



4. **Teenagers and Young Adults**: to address the specific needs of teenagers and young adults (TYA), in cooperation with adult oncology.



5. Quality of Survivorship: to address the consequences of cancer treatment such as long-term complications, to better understand the genetic background/risk of an individual, and to improve quality of life of childhood cancer survivors.



6. **Causes of Cancer**: to understand the causes of paediatric cancers and to address prevention wherever possible.



7. **Big Data and Artificial Intelligence:** to develop the infrastructure to implement Big Data and Artificial Intelligence research and innovation to the benefit of children and young people with cancer.



FUTURE PERSPECTIVE AND STRATEGIC OBJECTIVES FOR 2021-2026 SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)



Objective 1: Addressing Inequalities

To bring about equal access to standard care, expertise and clinical research for diagnosis, treatment and follow-up across Europe and to promote patient involvement and a patient-centred approach throughout.

Addressing national and international inequalities for children and young people with cancer is a fundamental strategic aim for SIOP Europe, which is relevant to all aspects of the care of children and young people with cancer. SIOP Europe will undertake significant actions to lower the inequalities across Europe in several key domains including:

- → Equal access to standard diagnostics and treatments, including essential medicines, across Europe
- → Equal access to innovative treatments across Europe (See Objective 2)
- → Equal access to information about and participation in clinical trials and research for childhood and adolescent cancer across Europe
- Equal access to specific treatment facilities for Teenagers and Young Adults with cancer (See Objective 5)
- Equal access to standard long-term follow-up care and related survivorship issues (See Objective 6) 4



Action plan for the next 5 years (2021-2026)

Long-term sustainability and development of the **ERN PaedCan**

The continued success of the ERN PaedCan is pivotal to achieving our objective of reducing inequalities for children and young people with cancer across Europe. It will be important to extend ERN PaedCan network into all European countries.

The ERN PaedCan will promote the establishment of Regional, National or European virtual tumour boards to ensure that all patients with a new diagnosis or in relapse are discussed and have access to recommended standard treatment options and, when relevant, are offered access to innovative therapies in clinical trials through appropriate referral pathways.

SIOP Europe and ERN PaedCan will continue to work with the ECTGs and CCI Europe to support the development and dissemination of the European Standard Clinical Practice (ESCP) guidance documents as part of the roadmap for guiding expert-driven clinical care across all common childhood cancers. The expected impact will be an increase in early and accurate diagnosis and effective treatment aligned with best standard practice as determined by disease-specific experts.

Equal Access to best standards of care in radiotherapy:

SIOP Europe now has a vibrant Radiation Oncology Working Group, which is addressing the challenges and setting standards for radiotherapy across Europe.



FUTURE PERSPECTIVE AND STRATEGIC OBJECTIVES FOR 2021-2026 SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)



The QUARTET Project aims to improve radiotherapy treatments in children and adolescents by reducing the risk of local recurrence and long-term toxicity through prospective quality assurance. The project will continue to develop and work towards establishing standards for quality assurance in paediatric radiotherapy. This outstanding initiative will contribute to improving general disease management in paediatric tumours in Europe. The QUARTET group will continue to work on projects that will support the standardisation of radiotherapy practice and support the delivery of high-quality radiotherapy, such as guidelines for the delineation of and the dose constraints for organs at risk. It is expected to deliver prospective RTQA programmes for an increasing number of clinical trials over the next 5 years. It is anticipated that at least three more trials will open to recruitment later in 2021.

Other groups of healthcare professionals dealing with children with cancer have shown interest in the use of a QUARTETtype platform for imaging review, but also for surgery and even pathology review.

Equal Access to best standards of care in imaging and interventional radiology:

SIOP Europe aims to build on the success of the Radiation Oncology Working Group and the QUARTET project and work with paediatric radiologists across different disease specialities to create a Radiology/Imaging Working Group to address the challenges in diagnostics and interventional radiology in childhood cancer. We will also explore the options to establish a centralised imaging platform to support research.

Equal Access to Essential Medicines:

On the basis of the JARC Conclusions, SIOP Europe has mobilised the pan-European community of clinicians, researchers, and parents to take part in the development of a list of anticancer medicines that are essential for the treatment of children and adolescents with cancer.

Based on current standard treatment protocols in all paediatric tumour types, literature review, and expert consensus, the SIOP Europe Essential Medicines List will be presented to EU policymakers and the WHO for the next revision of the WHO Essential Medicines List for Children (EMLc) 2021. This will be monitored to further improve the WHO list as part of the WHO Global Initiative for Childhood Cancer. In addition, SIOP Europe will work to address the main hurdles in accessing these essential medicines across Europe as identified (shortages, out of pocket costs, unavailable age-appropriate formulations) with a message: essential medicines to cure children with cancer should be available and accessible for each adolescent in Europe 24/7.

In addition, SIOP Europe will work with ACCELERATE with the goal to facilitate access to newly approved effective anti-cancer medicines for childhood cancer and a more aligned and accelerated evaluation by Health Technology Assessment bodies across Europe.

Equal access to information about and participation in clinical trials and research for childhood and adolescent cancer across Europe

SIOP Europe will take actions to raise awareness and promote all existing clinical trials that are currently run in Europe. The complete overview of the trials and projects will be published in SIOP Europe's Annual Report to facilitate information access for parents' and patients' representatives.





Objective 2: Precision Medicine and Treatment innovation

Development of new, safer and more effective therapies and improved multi-factor risk classification (including molecular and immunological factors) to help guide decisions on which therapies to use.

The challenge is to accelerate the development of innovative treatments in a more favourable and better incentivising environment and their introduction in the standard of care of poor prognosis malignancies. The goal is also to install precision medicine in the standard of care to best propose optimal treatment to each patient. There is currently an extraordinary momentum in the community with the ITCC New Strategic Plan which is being implemented with the SIOPE European Clinical Trial Groups. In addition, **ACCELERATE** has created a new mindset of working together, with all stakeholders (academia, industry, parents and advocates, regulators, and soon HTA bodies representatives), which is already impacting the field.

Action plan for the next 5 years (2021-2026)

- > Develop and introduce effective and less toxic innovative therapies and standard care.
- > Foster biology-driven therapeutic interventions and ensure equal access to innovation and precision medicine.
- > Elucidate the role of the immune system and epigenetics for therapeutic interventions.
- Actively contribute to shaping a new regulatory environment that will facilitate prioritisation of compounds to be developed and address the unmet needs of children and adolescents with cancer.
- Support and promote a science-driven development of new anti-cancer medicines based on paediatric tumour biology and preclinical evaluation through the early start of paediatric clinical evaluation.







Objective 3: Tumour biology

To foster increased knowledge of tumour biology and speed up translation from basic research to clinical care to benefit patients.

The landscape for tumour biology is evolving rapidly with emerging scientific technologies and innovations that are improving our understanding of the drivers of many cancers and opening opportunities for ground-breaking therapeutics, for example, the immunotherapeutic for childhood leukaemia and for neuroblastoma. SIOP Europe has highlighted the major need for sustainable international research platforms and collaborations through frameworks for structured collection, storage, and use of big data and artificial intelligence to deliver tailored solutions across the patient pathway (Kearns et al 2019). **Launched by the Mission Board for Cancer to the European Commission** was the proposal for a Horizon Europe Cancer Mission's 11th recommendation for a focus on **Cancers in children**, **adolescents, young adults: cure more and cure better**. If implemented, it should provide the paediatric oncology community with an unprecedented opportunity to address the disparities across Europe in levels of research funding for cancer in children and young people.

Action plan for the next 5 years (2021-2026)

- Continue to advocate for a visionary European research agenda to enable tangible change for children and adolescents with cancer and equalise survival across Europe.
- Foster more research on childhood cancer predisposition and the oncogenic drivers for cancers arising in childhood.
- Support research questions on the environmental causes of paediatric cancer through scientifically led and evidence-based studies.
- Promote systematic whole genome sequencing and other relevant 'omic platforms for all paediatric cancers at diagnosis and relapse with the possibility for pan-European data sharing for research.
- Stimulate inter-disciplinary discovery science to understand molecular and genomic drivers of paediatric and adolescent cancers.
- Promote working scientific brainstorming on tumour biology during SIOPE Annual Meetings
- Lead the childhood and adolescent cancer track for the Coordination and Supportive Action (CSA) of UNCAN.eu – a European Initiative to Understand Cancer: Recommendation 1 in the bold actions for the Horizon Europe Cancer Mission.







Objective 4: Teenagers and Young Adults

To address the specific needs of teenagers and young adults (TYA), in cooperation with adult oncology.

The needs of teenagers and young adults with cancer span all the SIOP Europe strategic objectives but with unique dimensions that require special focus and wider engagement with professional and patient organisations that are focused on the AYA healthcare, research and political agenda. **The SIOP Europe AYA Committee** will continue to work closely with existing networks including the ESMO-SIOP Europe Working Group, the European Network for Teenagers and Young Adults with Cancer (**ENTYAC**) as well as other SIOP Europe Working Groups.





- Increase the footprint of AYA in clinical trials through working with the relevant disease-specific clinical trials groups to include AYA when designing trials for diseases that span the age groups and develop trials for cancers that have a specificity for the AYA patients, for example, some soft tissue sarcomas.
- Enable access for adolescents to relevant clinical trials normally designed for the adult cancer patient population.
- Define the pathways of care and standards of treatment for Teenagers and Young Adults with cancer and focus on training and dissemination of guidelines to healthcare professionals, patients, carers and others.
- Increase the spotlight on AYA within the EU Commission programmes and increase the understanding and awareness of the needs of AYA in cancer policies at the national and European level. Specifically, promote the need for funded specialist AYA cancer services.
- Support an evidence-based research proposal about different models of AYA care across the EU comprehensive cancer centres/children's hospitals.
- Address the need for a specialist AYA workforce in terms of education and accreditation.
- Map current and funded research studying AYA cancer biology and aetiology in Europe.
- Work with and support the growing AYA-specific patient, parent and carer voice.





Objective 5: Quality of survivorship

To address the consequences of cancer treatment such as long-term complications, to better understand the genetic background/risk of an individual, and to improve quality of life of childhood cancer survivors.

SIOP Europe will further build its partnership with PanCare and CCI Europe towards a sustainable infrastructure in Europe for long-term follow-up research and care related to all survivorship issues.

Action plan for the next 5 years (2021-2026)

- Continue the collaboration with and within the PanCareSurPass project (2021-2024) to widely implement the SurPass to improve survivorship care for survivors of childhood and adolescent cancer in Europe together with PanCare and CCI Europe.
- Continue the work within the ACCELERATE Platform to make long-term follow-up of complications of treatment with novel agents prospective and complete with the set-up of a new registry/repository.
- Continue the work in PanCareFollowUp to spread the set-up of person-centred care in long-term follow-up of former childhood cancer patients through a Replication Manual.
- Develop and conduct a series of educational events on long-term complications of treatment and survivorship issues.





Objective 6: Causes of cancer

To understand the causes of paediatric cancers and to address prevention wherever possible.

There is an increasing emphasis on strategies for cancer prevention on the European Policy agenda, notably in Europe's Beating Cancer Plan because a substantial proportion of adult malignancies are potentially preventable. However, there are no known alterable risk factors for most childhood cancers. Up to 10% of paediatric cancers occur within a known genetic predisposition but genetic predisposition as the major known cause of childhood cancer remains under-explored.

Action plan for the next 5 years (2021-2026)

- Continue to advocate for a comprehensive public research programme on childhood cancer that holds the potential to unlock such new horizons and enable preventive strategies and programmes, which have been almost non-existent in the paediatric cancer field to date.
- Promote and support biology research to understand potential environmental causes for the development of childhood cancer.
- Through the work of the SIOPE Host Genome Working Group (HGWG), we will continue to:
 - o Study the cancer epidemiology and biology of individuals with cancer predisposition syndromes (CPS).
 - o Study the genetic and environmental cancer risk modifying factors in individuals with a CPS.
 - o Share and grow expertise in the interpretation of cancer predisposition gene (CPG) variants.
 - o Promote improvement in the diagnosis, psychosocial support and counselling for individuals with CPS.
 - o Develop cancer prevention strategies for individuals with CPS.
 - o Optimise cancer surveillance for individuals with CPS.
 - o Improve cancer treatment of patients with CPS by close collaboration with trial groups.
 - o Collaborate with family support organisations and educate families and health professionals in the host genome field.
 - o Study the genetic component of adverse treatment reactions.
 - o Harmonise care standards and diagnostic procedures for individuals with CPS within Europe.
 - o Study health economic aspects related to CPS.





Objective 7: Big Data and Artificial Intelligence

To develop the infrastructure to implement Big Data and Artificial Intelligence research and innovation for the benefit of children and young people with cancer.

In the next decade, there will be vast opportunities to translate artificial intelligence (AI) and Big Data into clinical practice but there is a long way to go before achieving an impact on childhood cancer patient outcomes. Further progress in the diagnosis and treatment of childhood cancers will require multidisciplinary integrated healthcare and research data platforms that enable real-world data simulations of machine-learning algorithms and AI in data-driven clinical decision support applications for the benefit of patients. The novel technologies of AI and Big Data can advance potentially life-saving research and use of information efficiently to underpin long-term follow-up care as well as to understand the causes of childhood cancer. We must ensure that Europe's children and youngest citizens affected by cancer can fully partake, and benefit from the emerging AI, Big Data and machine-learning technologies.

SIOP Europe is already a partner in the **PRIMAGE** European research project which offers an open cloud-based platform to support decision making in the clinical management of two paediatric cancers, Neuroblastoma (NB), the most frequent solid cancer of early childhood, and the Diffuse Intrinsic Pontine Glioma (DIPG), the leading cause of brain tumour-related death in children. The achievements of PRIMAGE are already visible for the scientific community including not just improvements from the technological point of view but by exploring the many aspects of this project in the imaging biomarkers in childhood cancer management. PRIMAGE is currently on the right track until the decision support system tool to help radiologists and oncologists with the management of NB and DIPG diseases in the future is fully developed.

Whilst AI can be a powerful game-changer, meaningful integrated data analyses inevitably need large datasets, and this is only achievable in the rare disease setting that characterises childhood and adolescent cancers if multiple datasets can be shared, integrated, and analysed as one. The datasets will need to follow the 'FAIR' principles, i.e., be findable, accessible, interoperable, and reusable if they are to benefit progress in childhood cancers.







Action plan for the next 5 years (2021-2026)

SIOP Europe's ambition over the next 5 years is to:

- Develop the multi-stakeholder infrastructure to implement Big Data and AI research and innovation for the benefit of children and young people with cancer.
- > Enable systematic use of all available research and healthcare data.
- SIOP Europe is collaborating with the EU4Child project on establishing a pan-European multi-national paediatric cancer Big Data initiative that will facilitate access to and integration of multiple paediatric cancer datasets with the aim of making them findable, accessible, interoperable and reusable (FAIR) for research with the purpose of improving diagnosis, treatment and outcomes for all children and young people with cancer and survivors and increasing the understanding of the underlying causes of childhood cancers. Such an initiative will explore how large-scale data integration, innovative analytics, machine learning, and AI could be applied to accelerate research and enhance the lives of children and adolescents with cancer. This project will support research and further collaboration on AI technologies applied for diagnosis and treatment of paediatric cancers. The aim is to create a multi-stakeholder network to connect and facilitate the exchanges and dissemination of best practices in clinically relevant Machine-Learning and Artificial Intelligence technologies between all relevant stakeholders, including paediatric oncology, technology developers, and ERN PaedCan and interrogate their application in relation to multi-national large-scale data sets and will build on existing EU-funded projects such as, for example, the Paediatric Rare Tumours Network PARTNER project.
- The European Health Data Space Roadmap is focused on eradicating inequalities, facilitating research, and empowering patients. The roadmap objective 1: 'Legal and governance framework to cover the access to and exchange of health data' is particularly relevant for addressing the challenges and opportunities in the paediatric cancer sector. SIOP Europe will continue to advocate for an interoperable and secure European Health Data Space including through EU consultations.





SIOP Europe's Cross-Cutting Agendas

Oncopolicy Programme

Action plan for the next 5 years (2021-2026)

Europe's Beating Cancer Plan

On 4 February 2020 – World Cancer Day, the President of the European Commission Ursula von der Leyen announced the launch of a Europe's Beating Cancer Plan Communication meant to underpin future policy efforts in this field. The European Commission conducted two public consultations to obtain citizens' perspectives on the content of Europe's Beating Cancer Plan. SIOP Europe in collaboration with CCI Europe and PanCare made an extensive effort to encourage input from members across Europe including 3 webinars. As a result, 200 responses were sent, and the European Commission has dedicated an entire section to childhood cancer in the breakthrough 'Helping Children with Cancer Initiative'.

SIOP Europe will continue advocating for appropriate inclusion and high visibility of paediatric cancer under the Flagship Initiative 'Helping Children with Cancer' inside Europe's Beating Cancer Plan and its implementation.

A Pharmaceutical Strategy for Europe: Timely Patient Access to Affordable Medicines

Launched by the European Commission on 2 June 2020, the Strategy aims to ensure Europe's supply of safe and affordable medicines to meet patients' needs and support the European pharmaceutical industry's innovation efforts. The Strategy concept note refers among others to the evaluation of the Paediatric Regulation and mentions a Plan on medicines shortages. SIOP Europe implemented a comprehensive stakeholder mobilisation effort to ensure that paediatric cancer community views are well represented, including an organisation of 2 webinars which resulted in high engagement.

- Advocacy on improving access to medicines for children and adolescents with cancer including in relation to legislation that enables faster and more efficient development of innovative therapies, countering shortages, and advancing affordable prices of new expensive agents – will remain key in the SIOP Europe agenda.
- Advocating for legislation that enables faster and more efficient development of innovative medicines for children and adolescents with cancer remains on the top of the policy agenda in the aftermath of the evaluation of the Paediatric and Orphan Regulations.

EU Funding Programmes in Health and Research

EU-level support is instrumental to ensure that the urgent needs of paediatric cancer patients and survivors are not overlooked and instead become an integral part of all relevant funding programmes. The Mission Board for Cancer announced in 2020 a cross-cutting recommendation 11 on 'Childhood cancers and cancers in adolescents and young adults: cure more and cure better' to maximise the impact of the Mission on Cancer. Hence, the Cancer Mission Area in the EU Framework Programme for Research and Innovation as well as the EU4Health Programme are among the initiatives that hold promise for a transformational change in the paediatric cancer sector in the years to come.

SIOP Europe will continue raising awareness on the unmet needs and the importance of specific EU-level support to paediatric cancers earmarked across all relevant EU programmes to make progress in research and ensure the sustainability of the ERN PaedCan.



Essential Medicines List for Children and Adolescents with Cancer

On the basis of the JARC Conclusions, SIOP Europe has mobilised the pan-European community of clinicians, researchers, and parents to take part in the development of a list of anticancer medicines that are essential for the treatment of children and adolescents with cancer.

Based on current standard treatment protocols in all paediatric tumour types, literature review, and expert consensus, the SIOP Europe Essential Medicines List will be presented to EU policymakers. The first set of project inputs was delivered to WHO for the 2021 revision of the WHO Essential Medicines List for Children (EMLc).

National Cancer Control Programmes (NCCPs)

The JARC findings highlighted that the inclusion of paediatric cancer in NCCPs was uneven across Europe, with only a few countries addressing it in a comprehensive manner.

SIOP Europe will generate further evidence on the status of paediatric cancer in NCCPs and foster its comprehensive inclusion according to the JARC policy recommendations.

ERN PaedCan and cross-border healthcare

The full potential of the ERN PaedCan necessitates sustainable funding but also an enabling cross-border healthcare environment. The JARC formulated concrete recommendations on the needs of paediatric cancer patients and their families in cross-border care.

SIOP Europe will work with all stakeholders to streamline the implementation of the cross-border healthcare Directive and the S2 reimbursement mechanism to reduce the burden on parents and patients and ensure appropriate compensation for virtual advice and opportunities for cross border access to clinical trials.

Keeping paediatric cancer high on the EU agenda

The policy term 2019-2024 is marked by a pronounced focus on cancer, as exemplified by the launch of Europe's Beating Cancer Plan and the Cancer Mission Area and the creation of the European Parliament Special Committee on Beating Cancer and Intergroup on Cancer.

- SIOP Europe will continue engaging with policy makers from all three EU institutions and other stakeholders to ensure that children and adolescents with cancer are at the forefront of the EU cancer agenda.
- SIOP Europe with CCI Europe is calling for the creation of the EU Childhood Cancer Advisory Board that would support the coordination of actions across all relevant EU initiatives, including among others, Europe's Beating Cancer Plan, the Horizon Europe Mission on Cancer, and the Pharmaceutical Strategy for Europe. The proposed vision is to foster a comprehensive inclusive approach, avoid the risk of fragmentation and accelerate the advancement towards the overall objective to cure more children, cure them better, and reduce inequalities.





Education and Training

Action plan for the next 5 years (2021-2026)

SIOP Europe Course

The virtual kick-off meeting of the new SIOP Europe Course in Paediatric Oncology took place in March 2021. The content and set-up of the course will include innovative learning strategies and state-of-the-art education adding to, not replacing, current oncology training courses.

The course is aimed at fellows in paediatric haematology and oncology and junior faculty at academic medical centres from across Europe and attendees will obtain the skills and expertise necessary to become leading physicians performing high-quality patient management and research.

Young SIOPE Mentorship Programme

This Early Career Involvement project for Young SIOPE members aims to provide the opportunity for junior colleagues to become engaged in the European Clinical Trial Groups (ECTGs) and, with the support of the ECTG community, to train and educate future ECTG members.

ECTGs will hopefully benefit from the diversity of the pan-European background of Young SIOPE members and their early-career "out-of-thebox-thinking" approach. The key element for this project to be successful will be mutual engagement between young members and experienced members of the paediatric cancer community.



Collaborative Activities

The aim is to further continue the highly valuable collaborative initiatives already established with ESO (Masterclass, e-Learning, Fellowship Programme), ESMO, ERN (European Standard Clinical Practice Recommendation documents for all types of cancer) and other partners and to seek such opportunities. Courses in collaboration with PanCare and the SIOPE Host Genome Working group are already scheduled. Collaborative courses with CCI Europe, as well as with the other SIOPE Working Groups (AYA, Radiation Oncology, Nurses, Palliative and Psychosocial) may be established as well.

SIOP Europe Long-term Fellowship

This long-term fellowship should provide early-career paediatric oncologists in European low- and middle-income countries the support and resources needed to advance their training by deepening their relationship with a mentor in a high-income European country. During the one-year fellowship, applicants receive valuable training and education, which they will use to effect change in cancer care in their home country/institution. Recipients are expected to return to their home institutions within one year of finishing the fellowship and disseminate/use the knowledge they have gained.



SIOP Europe – a Society serving its members

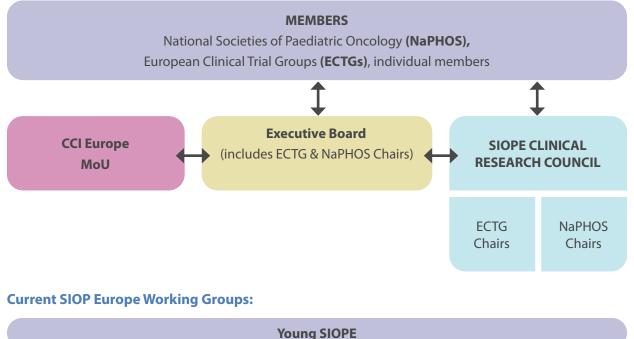
Action plan for the next 5 years (2021-2026)

SIOPE was established in 1998 as the European branch of SIOP (International Society of Paediatric Oncology). In 2007, following the revision of its Statute, SIOPE became an independent organisation, with a permanent Secretariat in Brussels and a professional structure. In 2011, the concept of the SIOP Europe Clinical Research Council was developed bringing together the leadership of the European NaPHOS and ECTGs to define and address the needs of the paediatric oncology community.

Over the last 3 years, several SIOP Europe Working Groups have been established bringing together the multi-national individuals invested in a specific aspect of paediatric oncology to collaborate to deliver defined aims and objectives within the SIOP Europe Strategic Plan.

To further the ambitions of SIOP Europe to support the paediatric oncology community and deliver our mission, SIOP Europe will further develop our partnerships with all stakeholders invested in the care and support of children and young people with cancer, including strengthening our links with NaPHOS and ECTGs, CCI Europe and PanCare, as well as other relevant stakeholders in Europe and globally.

SIOPE Clinical Research Council



SIOP Europe AYA Committee
SIOP Europe Radiation Oncology Working Group
SIOPE Host Genome Working Group



FUTURE PERSPECTIVE AND STRATEGIC OBJECTIVES FOR 2021-2026 SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026)



Working for the Paediatric Oncology Community

Many objectives have been reached by the different SIOP Europe Boards that have been in place over the past two decades. However, the landscape for paediatric and adolescent cancers has evolved and changed, such that additional actions must be envisaged and planned for the upcoming years to keep pace with these changes. SIOP Europe will work with the paediatric and adolescent oncology community to:

- Define and steer the scientific agenda for cutting-edge translational and clinical research in paediatric and adolescent haematology and oncology in Europe and drive the research methodology by exploiting all the possible information sources including the use of Big Data and Artificial Intelligence. These efforts should focus on how to overcome the bottlenecks derived from the data protection legislation, namely the General Data Protection Regulation (GDPR).
- Promote the implementation of patient-centred research; the European Patient Reported Outcomes (PRO) Roadmap is focused on implementing PRO in paediatric oncology clinical trials, facilitating research, and empowering parents and patients. SIOP Europe will enable dialogue across social, psychological and life sciences, which will be essential in the development of a nonprescriptive, participatory and outcome-oriented approach to research.
- Continue to monitor and engage with the overarching European research environment with respect to policies, grant calls and regulations. SIOP Europe will engage with the associated opportunities and harmonise joint initiatives for research and funding (e.g., international meetings, European calls, industry proposals for relevant scientific initiatives).
- > Enable the realisation of intergroup and international initiatives with a special focus on areas of inequalities.
- Reinforce activities in cooperation with the ERN PaedCan to strengthen its efficacy in enabling delivery of the best possible care wherever children and adolescents with cancer are diagnosed and treated in Europe, including fostering virtual tumour boards and cross-border care.
- Foster networking activities between the ECTGs and NaPHOS at the national and international level with the aim of overcoming inequalities in diagnosis, treatment, essential medicines availability, transition to adulthood and long-term follow-up to prevent and manage long-term complications.
- Provide support to ECTGs and NaPHOS in delivering their activities through organisational, administrative, logistical, and secretarial support.
- + Further develop and sustain training and education activities supported by the SIOP Europe community.

Evolving SIOP Europe Working Groups

SIOP Europe will support and promote the development of SIOP Europe Working Groups (WG) that address specific areas of care and research for the benefit of children and young people with cancer in Europe. Currently, four specific WGs exist within SIOP Europe, all of which have contributed substantially towards the goals of the SIOP Europe Strategic Plan. We will foster the development of new Working Groups, where there is a need and the objectives align with the SIOP Europe Strategic Plan. The WGs' Terms of Reference will be publicly available on the SIOP Europe website and their activities and achievements reported to the Community on an annual basis.







Sustaining the SIOP Europe Annual Meeting



The establishment of the Annual Meeting has been a major achievement of SIOP Europe. Its aim was to have a distinct characteristic that separates it from other traditional medical congresses, in that its principal focus is on networking. The aim is to bring together the diverse stakeholders involved in facing key issues for children and adolescents with cancer, with the declared intention of increasing the cure rates and improving the quality of life for survivors. The successful partnership with CCI Europe has ensured the excellent representation and participation of childhood cancer parents and survivors and provides exceptional possibilities for collaboration across all stakeholders within the paediatric oncology community.

SIOP Europe is committed to continuing to deliver this Annual Meeting, ideally face to face, to further promote the strengthening of our collaborative European multi-stakeholder community dedicated to the holistic needs of children, teenagers, and young adults with cancer.

Within future meetings, we will aim to:

- Increase the Joint Sessions and Networking opportunities.
- Foster the participation of attendees coming from outside the European Clinical Trial Groups, European National Paediatric Haemato-Oncology Societies and CCI Europe, for example, scientists, clinicians, and researchers belonging to different subspecialty areas, young physicians and nurses, patients, survivors, policymakers and healthcare professionals.
- Promote multi-stakeholder discussions and debates on important cross-cutting tumour topics and best practice.
- → Increase the number of exhibitors and partners.

Maintaining the SIOP Europe Communications and Information dissemination strategy

The fundamental principles of sharing and openness will continue to guide the proactive style of communicating SIOP Europe's vision and goals for the future. While many initiatives in past communications plans have been effectively implemented and led to improvements, it is important to remain proactive with regards to the challenges and opportunities such as:

- Continued and improved two-way engagement with our various audiences and stakeholders to actively engage them in meaningful dialogue.
- Creating a dedicated Online Members Area to enable members to access relevant information.
- Creating a database/membership system where each member and non-member will be able to have a unique profile.

SIOP Europe will continue monitoring the needs of our members, community, and stakeholders as we continue to explore virtual educational/learning platforms, especially within the ongoing health emergency.







Contact

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Relevant External Links

SIOP Europe

- Clinical Research Council for paediatric and adolescent oncology: https://SIOP Europe.eu/European-research-and-standards/clinical-research-council/
- C SIOP Europe Annual Meeting: <u>www.SIOP Europeurope.eu</u>
- SIOP Europe AYA Committee: <u>https://siopeSIOP Europe.eu/siop-europeEurope-aya-committee/</u>
- C SIOP Europe Educational Opportunities: <u>https://SIOP Europe.eu/activities/education</u>
- C SIOP Europe Oncopolicy Programme: <u>https://SIOP Europe.eu/activities/European-advocacy/</u>
- SIOP Europe Publications : <u>https://SIOP Europe.eu/publications/</u>
- SIOP Europe Radiation Oncology Working Group: https://siope.eu/siop-europe-radiation-oncology-working-group/
- SIOP Europe: <u>https://SIOP Europe.eu/</u>
- C SIOPE Host Genome Working Group: <u>https://siope.eu/siope-host-genome-working-group/</u>
- C THE SIOP EUROPE STRATEGIC PLAN 2015: https://SIOP Europe.eu/media/wp-content/uploads/2018/02/the-SIOP Europe-strategic-plan.pdf
- ✓ Young SIOPE: <u>https://siope.eu/young-siope/</u>

Projects & Platforms

- CACCELERATE (international multi-stakeholder platform to improve the global development of new paediatric oncology drugs): <u>https://www.accelerate-platform.org/</u>
- C conect4children (c4c) project: <u>http://www.conect4children.org/</u>
- C ERN PaedCan, European Reference Network on Paediatric Cancer: https://paedcan.ern-net.eu/
- CEU Joint Action on Rare Cancers (JARC): https://siope.eu/activities/eu-projects/eu-joint-action-rare-cancers-jarc/
- PanCareFollowUp Novel, patient-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for survivors and caregivers: <u>https://pancarefollowup.eu/</u>
- PanCareLIFE Life after Childhood Cancer: <u>http://www.pancarelife.eu/</u>
- PanCareSurFup PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies: <u>https://www.pancaresurfup.eu/</u>
- Z PARTNER Project, Paediatric Rare Tumours Network European Registry: https://www.raretumors-children.eu/partner-project/
- PRIMAGE Predictive In-silico Multiscale Analytics to support cancer personalised diagnosis and prognosis, Empowered by imaging biomarkers: <u>https://www.primageproject.eu/</u>
- C QUARTET: Excellence in Radiotherapy for Children and Adolescents with Cancer: https://siope.eu/activities/joint-projects/quartet/
- C Survivorship Passport (for childhood cancer survivors): <u>https://siope.eu/activities/joint-projects/survivorship-passport/</u>
- C The ExPO-r-Net Project: <u>https://www.expornet.eu/</u>
- C TREL Project Twinning in Research and Education to improve survival in Childhood Solid Tumours in Lithuania: https://siope.eu/TREL-project





Partnerships

- CCI Europe: <u>https://ccieurope.eu/</u>
- European Cancer Organisation: <u>https://www.Europeancancer.org/</u>
- European School of Oncology ESO: <u>https://www.eso.net/</u>
- European Society for Medical Oncology ESMO: <u>https://www.esmo.org/</u>
- European Society for Therapeutic Radiology and Oncology ESTRO: <u>https://www.estro.org/</u>
- Innovative Therapies for Children with Cancer ITCC: <u>https://www.itcc-consortium.org/</u>
- International Society of Paediatric Oncology SIOP: <u>https://siop-online.org/</u>
- PanCare: <u>https://www.pancare.eu/</u>

Oncopolicy Publications

- 6 Key Recommendations for Boosting Innovation and Access to Paediatric Anticancer Medicines (November 2020): <u>https://siope.eu/media/documents/recommendations-for-paediatric-cancer-following-launch-of-the-pharmaceutical-strategy-for-europe.pdf</u>
- A Europe for Children & Adolescents with Cancer: Position paper of the European paediatric cancer community (January 2021): <u>https://siope.eu/media/documents/a-europe-for-children-adolescents-with-cancer-dont-leave-them-behind-position-paper-of-the-euro.pdf</u>
- A European Paediatric Cancer Mission: Aspiration or Reality? (September 2019): <u>https://siope.eu/news/european-paediatric-cancer-mission-aspiration-or-reality/</u>
- Beating Cancer in Europe: Let's not forget our children and adolescents (February 2020): <u>https://worldspanmedia.s3.amazonaws.com/media/siope/documents/document/beating-cancer-in-europe_737480.pdf</u>
- Childhood Cancer European Elections Manifesto 2019 2024 (March 2019): <u>https://worldspanmedia.s3-eu-west-1.amazonaws.com/media/siope/PDF/SIOP-Manifesto-A5-vFINAL.pdf</u>
- European Parliament Health Committee (ENVI) Report: "Strengthening Europe in the fight against cancer: Going Further, Faster" (2020) (NB: Paediatric cancer content developed with SIOPE's contribution as of page 136, Section 4.2): https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/IPOL_STU(2020)642388_EN.pdf
- The Rare Cancer Agenda 2030: The Ten Recommendations from the Joint Action on Rare Cancers (September 2019) (NB: includes dedicated Paediatric Cancer Section developed by SIOPE at the end of each Chapter): <u>http://jointactionrarecancers.eu/attachments/article/265/Rare Cancer Agenda 2030.pdf</u>







Scientific Publications

- Access to essential anticancer medicines for children and adolescents in Europe (2002): <u>https://www.annalsofoncology.org/article/S0923-7534(20)43223-5/fulltext</u>
- Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) (2021): https://www.esmoopen.com/article/S2059-7029(21)00053-3/fulltext
- Challenges for Children and Adolescents With Cancer in Europe: The SIOP-Europe Agenda (2014): <u>https://onlinelibrary.wiley.com/doi/pdf/10.1002/pbc.25044</u>
- Creating a unique, multi-stakeholder Paediatric Oncology Platform to improve drug development for children and adolescents with cancer (2014): <u>https://www.ejcancer.com/article/S0959-8049%2814%2901065-X/fulltext</u>
- Current recommendations for cancer surveillance in Gorlin syndrome: a report from the SIOPE host genome working group (SIOPE HGWG) (2021): <u>https://pubmed.ncbi.nlm.nih.gov/33860896/</u>
- Organ at risk delineation for radiation therapy clinical trials: Global Harmonization Group consensus guidelines (2020): <u>https://www.thegreenjournal.com/article/S0167-8140(20)30294-2/pdf#.Xti61tAdvYw.twitter</u>
- Predisposition to cancer in children and adolescents (2021): <u>https://pubmed.ncbi.nlm.nih.gov/33484663/</u>
- Rationale of the rare cancer list: a consensus paper from the Joint Action on Rare Cancers (JARC) of the European Union (EU) (2020): <u>https://www.researchgate.net/publication/340227949 Rationale of the rare cancer list a consensus paper from the Joint Action on Rare Cancers JARC of the European Union EU</u>
- Selection criteria for assembling a pediatric cancer predisposition syndrome gene panel (2021): <u>https://pubmed.ncbi.nlm.nih.gov/34061292/</u>
- The spleen as an organ at risk in paediatric radiotherapy: A SIOP-Europe Radiation Oncology Working Group report (2021): <u>https://www.sciencedirect.com/science/article/pii/S0959804920313095?dgcid=coauthor</u>
- The SIOPE strategic plan: A European cancer plan for children and adolescents (2016): <u>https://siope.eu/media/wp-content/uploads/2013/06/PIIS2213538316300017.pdf</u>

Other links

- FAIR for AYA Stamps 2021: <u>https://www.accelerate-platform.org/fair-trials/fair-aya-stamps/</u>
- Global initiative for childhood cancer WHO: <u>https://www.who.int/docs/default-source/documents/health-topics/cancer/who-childhood-cancer-overview-booklet.pdf</u>
- Global Quality Assurance of Radiation Therapy Clinical Trials Harmonization Group: <u>https://rtqaharmonization.org/</u>
- Innovative Medicines Initiative (IMI): <u>https://www.imi.europa.eu/</u>
- ITCC P4: <u>https://www.itccp4.eu/</u>
- Luxembourg Foundation Kriibskrank Kanner: <u>https://fondatioun.lu/</u>
- C The Andrew McDonough B+ Foundation: <u>https://bepositive.org/</u>





List of acronyms/glossary

A.I.E.O.P.: l'Associazione Italiana di Ematologia e Oncologia Pediatrica

Biobank: A type of biorepository that stores biological samples (usually human) for use in research

Biomarker: Generally, refers to a measurable indicator of some biological state or condition

CCI: Childhood Cancer International / CCI Europe: Childhood Cancer International – Europe

CDDF: Cancer Drug Development Forum

CNS: Central Nervous System

COG: Children Oncology Group

CRC/ECRC: European Clinical Research Council for paediatric and adolescent oncology

CTF: Clinical Trial Facilitating platform

DG SANTE: Directorate-General for Health and Food Safety, European Commission

EAC: (ENCCA) Ethics Advisory Committee

ECTGs: European Clinical Trial group(s) in paediatric oncology

EICNHL: European Inter-group Cooperation on Childhood and Adolescent Non Hodgkin Lymphoma

EMA: European Medicines Agency

ENCCA: European Network for Cancer research in Children and Adolescents

EORTC: European Organisation for Research and Treatment of Cancer

EPAAC: European Partnership for Action Against Cancer

EpSSG: The European Paediatric Soft tissue sarcoma Study Group

ERN: European Reference Network(s)

ESMO: European Society for Medical Oncology

EU: European Union

EURAMOS: European and American Osteosarcoma Study Group

EXPeRT: The European Cooperative Study Group for Pediatric Rare Tumors

FaR-RMS: Over-arching study for children and adults with newly diagnosed and relapsed rhabdomyosarcoma (RMS). It is a multi-arm, multi-stage trial, involving several different questions.

FDA: Food and Drug Administration

FP5, **FP6**, **FP7**: EU 5th/ 6th/ 7th Framework Programmes for research and innovation

Horizon 2020: EU Programme for research and innovation (2014-2020)

HTA: Health Technology Assessment

I-BFM: International BFM Study Group

ITCC: Innovative Therapies for Children with Cancer

LTS: (ENCCA) Long-Term Sustainability (working group)

MAC: Members of the European Parliament (MEPs) Against Cancer Interest Group

MOA: Mechanism(s) Of Action

MoU: Memorandum of Understanding

NaPHOS: National Paediatric Haematology-Oncology Society-ies

PanCare: Pan-European network for Care of survivors after childhood and adolescent cancer

PanCareSurFup: PanCare childhood and adolescent cancer SURvivor care and Follow-UP studies

PICORET: Population Improvement in Childhood cancer Outcomes through Research, Evaluation and Training

PMDA: Pharmaceuticals and Medical Devices Agency

PPAC: (ENCCA) Parent and Patient Advocacy Committee

PROs: Patients Reported Outcomes

QUARTET: QUAlity and excellence in RadioTherapy and imaging for children and adolescents with cancer across Europe in clinical Trials

RTQA: Radiation Therapy Quality Assurance

SIOP EUROPE: SIOP Europe, the European Society for Paediatric Oncology

SIOPEL: SIOP EUROPE-Epithelial Liver Tumour Study Group

SIOPEN: SIOP Europe Neuroblastoma Group

SIOP-HRMB: An International Prospective Trial on High-Risk Medulloblastoma in Patients Older than 3 Years

SSH: Social Sciences and Humanities project

TACL: Therapeutic Advances in Childhood Leukemia and Lymphoma

TGA: Therapeutic Goods Administration

TYA: Teenagers and Young Adults

WHO EMLc: The WHO Model Lists of Essential Medicines for Children



LIST OF ACRONYMS/GLOSSARY SIOP EUROPE STRATEGIC PLAN UPDATE (2021-2026) The European Society for Paediatric Oncology Clos Chapelle-aux-Champs 30 1200 Brussels, Belgium



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