

# **THE SIOPE STRATEGIC PLAN REPORT**

**Achievements 2016**



# SIOPE Strategic Plan Report

## Achievements 2016

### Contents

Why Childhood Cancer Needs a Plan .....	2
Creation of the SIOPE Strategic Plan.....	3
Launch and First Steps in the Plan’s Implementation .....	5
The Achievements in 2016 .....	6
Achievements of Objective 1: Innovative treatments .....	6
Achievements of Objective 4: Equal Access.....	7
Achievements of Objective 5: Teenagers and Young Adults.....	8
Achievements of Objective 6: Quality of Survivorship .....	9
PLATFORMS.....	10
Cross-tumour programmes .....	11
Conclusion and the Next Steps.....	14





## Why Childhood Cancer Needs a Plan

**Cancer in young people is rare, but it is still a major health issue in Europe.** Although the survival rates for this disease greatly improved in Europe over the past fifty years – thanks to the multidisciplinary treatments developed by the paediatric haemato-oncology research community – more than 6,000 young people still die of cancer every year.

Survival rates have plateaued for some of these malignancies whilst other types of cancers still present a very poor prognosis and the long-term side effects of treatment still (often severely) affect the lives of two thirds of the 300,000 childhood cancer survivors currently living in the region.

Given this unacceptable situation, the European paediatric haemato-oncology community – represented by the European Society for Paediatric Oncology ([SIOPE](#)) – agreed that a consensus-based long-term plan would be needed to **increase the cure rate and the quality of long-term survival of children and young people with cancer by 2025.**



**Figure 1** - SIOPE Partners agreeing to the idea of a Strategic Plan for Paediatric Oncology at the SIOPE-ENCCA Conference in 2014



## Creation of the SIOPE Strategic Plan

The need for a Plan was first recognised in the framework of the European Network for Cancer research in Children and Adolescents ([ENCCA](#)), and the first drafts of the document were elaborated by the expert working group “[ENCCA Long Term Sustainability Working Group](#)”.

After the end of the ENCCA project, SIOPE took the lead of the Strategic Plan initiative. Constantly growing in scope and importance over the past 10 years, SIOPE is the only society addressing the challenges faced by all paediatric cancer professionals in Europe, representing today more than 1,600 members from 35 European countries.

In close cooperation with the European Clinical Trial Groups in paediatric oncology (ECTGs) and the National Paediatric Haematology-Oncology Societies (NAPHOS), as well as the parents, patients, and survivors’ advocates from the Europe Regional Committee of [Childhood Cancer International \(CCI\)](#), SIOPE partners strenuously worked over a few years to identify obstacles and formulate solutions to increase the disease- and late-effect- free survival after 10 years from the disease. At the same time, a broader consensus of all the European paediatric haematology-oncology community was sought.

Backed by an extensive endorsement, the final version of the [SIOPE Strategic Plan ‘A European Cancer Plan for Children and Adolescents’](#) sets up **7 medical and scientific objectives** for the next decade:



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



**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;



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



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



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



**Objective 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;



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



Figure 2 – A visual representation of the Plan’s 7 Objectives



## Launch and First Steps in the Plan's Implementation

The Plan was officially **launched on 18<sup>th</sup> November 2015 at the European Parliament**, during a key event hosted by MEP Alojz Peterle and co-organised by SIOPE and the 'MEPs Against Cancer' Group. On this occasion, more than 120 participants agreed that childhood cancer should always be a priority for the European Union, which should do more to save further children's lives and reduce survivors' adverse late-effects. A couple of months before, the European scientific community also welcomed the SIOPE Plan's initiative during the SIOPE Session at the 2015 European Cancer Congress.

Since the official launch of the Plan at the end of 2015, SIOPE took the lead in **coordinating the implementation** of the Strategic Plan. For instance, the SIOPE Board defined the leaders responsible for the implementation of each of the Plan's objectives, and the society strengthened its partnerships with patients, parents and survivors' advocates, adult oncologists, industry as well as paediatric oncologists from other continents.

Most importantly, several **cross-tumour platforms and projects** were initiated to address the critical variables that could facilitate the Plan's implementation:

- **QUARTET** (*Quality and Excellence in Radiotherapy and Imaging for Children and Adolescents with Cancer across Europe in Clinical Trials*): a project for quality assurance in radiation therapy;
- **ACCELERATE** (*Innovation for Children and Adolescents with Cancer*): a multi-stakeholder platform to improve oncology drug development for children and adolescents;
- **PICORET** (*Population Improvement in Childhood cancer Outcomes through Research, Evaluation and Training*): an outcome research project to evaluate and monitor progress in childhood cancer survival and therapy effectiveness;
- **Clinical Trial Facilitation (CTF)**: a platform to facilitate the setup of clinical trials within the new EU Clinical Trial Regulation;
- **'Ethics, Social Science and Humanities'**: a project to address the ethical aspects related to paediatric cancer;
- **SIOPE IT Portal**: an efficient IT infrastructure to support e-Health and research;
- **'Oncopolicy'**: a programme to ensure that the needs of young people with cancer will be considered into all EU policy initiatives in the field of health and research;
- **'Education and Training'**: a programme to ensure an adequate training to paediatric oncology health professionals;
- **Paediatric Oncology European Reference Network (ExPO-r-Net)**: a network of excellence to improve access to quality expert healthcare for paediatric cancer patients, thereby reducing outcomes' inequalities across Europe.

## The Plan's Objective/Platform & the Initiatives

### The Achievements in 2016

In 2016, SIOPE focused on the next steps in the Plan's implementation and made remarkable progresses carrying out several initiatives.

#### Achievements of Objective 1: Innovative treatments

##### ACCELERATE platform



- **Consolidation of the [ACCELERATE Multi-stakeholder Platform](#):** SIOPE partners have been working since 2013 with parents, patients and survivors as well as regulatory and industry experts in this unique platform to speed up life-saving innovation in paediatric oncology therapies. Over the past years, ACCELERATE partners managed to:
  - Produce proposals to revise the already mentioned EU Paediatric Regulation to better address the needs of children and adolescents with cancer (proposals already reflected in the recently voted Resolution);
  - Identify barriers and formulate possible solutions to set up drug prioritisation and enable drug development, propose new incentives for the development of specific paediatric drugs (and repurposing of existing drugs), as well as achieved long-term follow up measures for new oncology drugs;
- Raised general interest on this theme thanks to the successful ACCELERATE Conferences ([2016 edition](#): 4<sup>th</sup> CDDF – ITCC – SIOPE ACCELERATE Paediatric Oncology Conference, 20-21 January 2016, Brussels, BE).

##### Innovative Medicines & Oncopolicy Programme



- **European Parliament vote on the Resolution on the [EU Regulation on Paediatric Medicines](#):** this new Resolution is of utmost importance to the community, as it aims to influence the revision of the EU Paediatric Regulation (EC) No 1901/2006 and, thus, facilitate a better and faster access to innovative therapies for all children and adolescents will cancer in Europe. SIOPE and its partners (from Cancer Research UK, the MEPs against Cancer group of the European Parliament as well as from the [Unite2Cure](#) network of parent/patient advocates) took a leading role in contributing to this new Resolution, and this vote is the result of the intense work and advocacy campaign carried out within the [ACCELERATE multi-stakeholder platform](#).

## Achievements of Objective 4: Equal Access

### Equal Access



- **Successful application for the European Reference Network in Paediatric Oncology (ERN PaedCan):** in December 2016, the Board of EU Member States officially approved the -ERN PaedCan for which the [ExPO-r-Net](#) served as a pilot project. The ERN PaedCan will establish a clear framework for European healthcare providers to exchange expertise and provide cross-border healthcare for complex conditions across Europe. This incredible result has been achievable thanks to the great team effort and the strong commitment of ExPO-r-Net partners and all members during the assessment process.
- **Contribution to ECCO Essential Requirements for Quality Cancer Care – Sarcoma:** In 2016, SIOPE co-led a multi-disciplinary consensus-building project within ECCO – the European CanCer Organisation to define the fundamental elements of high quality care for sarcoma, including bone sarcoma in children and adolescents. SIOPE’s expert input was instrumental to consolidate and reach mutual agreement on the final recommendations regarding organisation of care and multi-disciplinary team composition necessary to ensure optimal outcomes for these patients across Europe.

### Equal Access



- **Leadership of the Childhood Cancers’ Work Package (WP9) of the Joint Action on Rare Cancers (JARC):** SIOPE has been selected as the leader of the Work Package 9 (WP9) ‘Childhood Cancers’ of the Joint Action on Rare Cancers (JARC), an important initiative of the EU and Member States addressing the absence of rare cancers – including paediatric cancers – from national cancer and rare disease plans across Europe. Co-financed by Member States and the European Commission, the JARC was officially launched on 7<sup>th</sup> November 2016 in Luxembourg. This initiative generated recommendations to improve health outcomes for patients with rare cancers, and undertake international research to concentrate their treatment of rare cancer patients in specialist multidisciplinary centres.

### Quality of Survivorship



More specifically, the focus of WP 9 is on:

- Access to essential medicines and innovative therapies;
- Extremely rare cancers;
- Models of healthcare for survivors.



## Achievements of Objective 5: Teenagers and Young Adults

To address the specific needs of teenagers and young adults



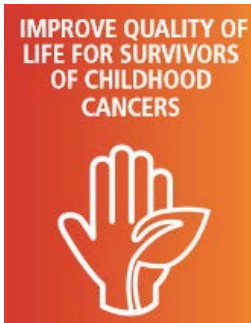
- **ESMO-SIOPE Cancer in AYA Working Group:** Following collaborative efforts in the educational arena between the two societies since 2014, the European Society of Medical Oncology (ESMO) and SIOPE created a Joint Working Group on Cancer in Adolescents and Young Adults (AYA) in 2016, into which each society delegated three representatives. The goal of the joint Working Group on Cancer in Adolescents and Young Adults (AYA) is to promote education in cancer topics specific to this population. Details about the group's aims and achievements can be found at: <http://www.esmo.org/About-Us/Who-We-Are/Educational-Committee/Adolescents-and-Young-Adults-Working-Group>

In brief, the AYA working group's main aim is to increase awareness amongst the medical and paediatric oncology communities and enhance knowledge on specific cancer issues in adolescents and young adults. It 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.

- Accomplishments achieved in 2016 were summarised in poster form at the 1<sup>st</sup> Global AYA Cancer Conference in Edinburgh, December 2016 (<http://www.esmo.org/content/download/111200/1943115/file/ESMO-SIOPE-Edinburgh-2016-Poster.pdf>). They include a Joint ESMO-SIOPE Symposium "From childhood to adulthood: Cancer in adolescents and young adults" held at the ESMO 2016 Congress. Several e-learning modules on AYA cancer were developed, further modules are either being completed or planned. Agreement on producing a joint handbook on AYA cancer was also achieved.
- Importantly, both societies launched a joint survey on AYA care, which was distributed to medical professionals from all over Europe. Objectives of the Survey were to record the current situation in AYA cancer care in Europe, to ensure the ESMO and SIOPE Joint Working Group provides educational content on AYA issues that is of interest to members of both societies, and to increase professional awareness of AYA cancer related issues. It consisted of seven parts: Demographics, services for AYA and clinical teams, clinical research and clinical trials, the health of people living after cancer, the management of cancer risk in AYA, involvement of patients and the public in improving AYA cancer outcomes and services, and professional education about AYA with cancer. Results were reported at the ESMO 2017 Congress in Madrid, which again also hosted a joint ESMO-SIOPE session on AYA oncology, and it was anticipated that they will appear in print simultaneously. The results of the ESMO-SIOPE Survey on AYA Cancer Care will guide the further activities of the joint AYA working group. The successful collaboration between Europe's leading Societies for Medical and Paediatric Oncology, ESMO and SIOPE, in a joint AYA Working Group may thus serve as a model and as an incentive for other regions of the world where the needs of AYAs with cancer are just as pressing.

## Achievements of Objective 6: Quality of Survivorship

### Quality of Survivorship



- **Development of the Survivorship Passport:** SIOPE is actively contributing to the development of the 'Survivorship Passport' initiative, included in the JARC as well as in the EU projects [ENCCA](#), [ExPO-r-Net](#) and [PanCareSurFup](#). The Passport addresses the general lack of information on the possible late effects stemming from the previous disease and treatments received. This online tool will provide access to the medical history of childhood cancer survivors, making survivors and healthcare professionals aware of the potential late effects. SIOPE is collaborating with other Survivorship Passport partners to:
  - Cross-check that the information available on the online platform is easy to understand and user-friendly;
  - Develop recommendation brochures – translated in the main European languages – for an adequate follow-up depending on individual risk factors;
  - The Survivorship Passport is starting to be integrated in EU Member States' National Cancer Plans. In 2015, it was included in the 5-year Austrian cancer plan for paediatrics. In September 2016, Childhood Cancer Switzerland, an organisation combining healthcare specialists, families, and survivors of childhood cancer, agreed to start introducing the Survivorship Passport in all Swiss paediatric hospitals. Similarly, the Italian Association of Paediatric Haematology and Oncology (AIEOP) has approved the Survivorship Passport for all the AIEOP centres. Belgium, Croatia, Germany, Lithuania, Portugal, and Spain are also considering its implementation.

## PLATFORMS

### Platform on Radiotherapy Quality Assurance



- **Launch of the project QUARTET:** On 20<sup>th</sup> May 2016, a group of European experts in paediatric cancer radiotherapy and imaging officially kicked-off the project QUARTET (*Quality and Excellence in Radiotherapy and Imaging for Children and Adolescents with Cancer across Europe in Clinical Trials*) in Brussels. High-quality radiotherapy in children and adolescents with cancer plays an essential role in achieving better patient outcomes. This 5 years project aims to reduce the risk of local recurrence and long-term toxicity. Thanks to the collaboration between SIOPE and the European Organisation for Research on Treatment of Cancer (EORTC), and to the support of the Luxembourg [Fondatioun Kriibskrank Kanner](#), QUARTET makes available a reviewing platform to ensure the quality of the radiation therapy and imaging provided in clinical trials for all paediatric malignancies.
- **QUARTET enrolled its first patients:** the first three patients have been already enrolled in the project and have been fully reviewed on the platform. Moreover, several clinical trial groups within the SIOPE framework agreed to use the QUARTET platform and have already started to work together on radiotherapy quality assurance. The project will soon cover patients treated for neuroblastoma, rhabdomyosarcoma, Wilms' tumour and brain tumours as part of eight European prospective clinical trials. It is to be expected that this project will be extended to even more – and maybe all – patients treated with radiotherapy in European paediatric oncology clinical trials.

### Platform on Epidemiology Outcome Research



- **PICORET integrated into the JARC:** PICORET (Population Improvement in Childhood cancer Outcomes through Research, Evaluation and Training) aims to enable prospective clinical observational studies that can look at outcomes (survival, quality of survival) in relation to detailed information on patient and tumour characteristics and treatment received. The aim is to enable descriptive outcomes research from the point of diagnosis through to long-term follow up, aligning with research conducted by the clinical trial groups and PANCARE (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) and promoting quality improvement. Partnerships between clinical and population based cancer registries will be initiated through the Joint Action on Rare Cancers, to improve the efficiency, quality and sustainability of clinical data capture. Twinning programmes will be developed through the ERN PaedCancer. Harmonised logistics for prospective observational studies will be tested in conjunction with the European clinical trial groups.
- The JARC Work Package on 'Epidemiology' will include some of the paediatric oncology needs identified by the PICORET project, which was previously submitted by SIOPE partners to the European Commission as a potential Horizon 2020 project. The aim is to use information from European registries and observational studies to monitor and evaluate progress in the survival of children and adolescents treated for cancer.



### IT Platform



- **Ongoing IT Developments:** the SIOPE IT partners from various EU-funded projects are currently developing different aspects of an integrated IT environment to implement the SIOPE Plan:
  - *Unique ID (EUPID) for Data Pseudonymisation* for the secondary use of data: this pilot integrated IT structure will allow clinical trial groups to register patients with a unique ID so that their data can be pseudonymised and shared between different databases (e.g. registries, clinical trial databases) and users (such as researchers and analysts) across Europe;
  - *Virtual Tumour Board Case Consultation Systems:* this online platform allows having multidisciplinary experts around Europe to exchange advice on diagnosis and treatment for rare cancers. Already developed for patients with hepatoblastoma, this IT tool is further developed within the ExPO-rNet project for retinoblastoma and extremely rare paediatric tumours;
  - *Survivorship Passport Database:* The Survivorship Passport tool is linked to a database storing the medical history and the clinical data of the survivor, allowing both doctors and survivors to access this information via a secured website and a mobile app.

## Cross-tumour programmes

### Oncopolicy Project



- **Leading role in the revision of the EU Paediatric Regulation & in the JARC:** In 2016, SIOPE was involved in several EU policy developments, as the only stakeholder to be consulted when European health and research policy initiatives related to paediatric cancers are being discussed. SIOPE effectively ensured that the needs of the paediatric haematology-oncology community were considered when these developments took place:
  - The inclusion of paediatric cancers in the JARC initiative (WP on Paediatric Cancers and WP on Epidemiology), which will pave the way for the inclusion of the needs of paediatric cancer in each National Cancer Plan in Europe;
  - The European Parliament vote on the Resolution on the EU Regulation on Paediatric Medicines on 15<sup>th</sup> December 2016, which is the result of an intense advocacy campaign carried out by SIOPE and its partners and benefitted from the support of several Members of the European Parliament;
  - The successful application for a paediatric oncology European Reference Network (ERN PaedCan), in the framework of the Cross-Border Healthcare Directive (2011/24/EU);

## Education Platform



- **Educational Opportunities:** SIOPE entered in several collaborative partnerships with other stakeholders to offer new and interesting education opportunities to its members and, thus, encourage the delivery of high quality paediatric oncology care and research:
  - *Partnership with ESMO:*
    - Activities linked to the [ESMO-SIOPE Adolescents and Young Adults Working Group](#);
  - *Partnership with ESO:*
    - The 6<sup>th</sup> [SIOPE-ESO Masterclass in paediatric oncology](#) in Berlin in 2016 was very successful and highly rated. The 7<sup>th</sup> Edition is already in preparation and will take place in Nauen (Berlin) on 16- 21 June 2018. The paediatric oncology masterclass is a clinically oriented educational programme for young Paediatric oncologists (30-40 years old) based upon practice oriented training and teaching sessions. The main topics will be CNS Tumours, Neuroblastoma, Soft tissue sarcoma, Bone tumours, Wilm's tumour, Acute lymphoblastic leukemia and Acute myeloid leukemia.
    - Admittance to the Masterclass is by competitive application. Participants will be directly involved in teaching activities with a Case presentation and interactive discussion with the Faculty and students.
    - [ESO-SIOPE e-sessions on Paediatric Oncology](#): SIOPE experts have been involved in delivering three online sessions on different aspects of childhood cancers. Moreover, two of the cases presented during the Masterclass – [a case](#) on adolescent sarcoma and [one](#) on refractory metastatic rhabdomyosarcoma – were uploaded on the ESO ePatCare platform for educational purposes, and are likely to be soon transformed into interactive format.
  - *Partnership with ECCO:*
    - [MCCR Workshop](#) (former Flims): SIOPE contributes to the next edition of this Workshop on Clinical Cancer Research for young investigators;
    - [SIOPE Society Day](#): this unique one-day educational conference took place on 27 January 2017, the first day of the European Cancer Congress ([ECCO2017](#)). This highly innovative programme for childhood cancer professionals illustrated the most effective approaches at the clinical and research levels.



**Platform “Clinical Trial Facilitation” (CTF)**



- **First presentations from the CTF:** At recent SIOPE events (e.g. the SIOPE General Assembly), the two leaders of this Platform have presented their first ideas on how to help institutions to set up international clinical trials in the framework of the new EU Clinical Trials Regulation (536/2014/ EU).

---

**Communication Platform**



- New social media strategy, including regular activity on Twitter and LinkedIn, has been implemented to help raise awareness on the challenges faced by children and adolescents with cancer in Europe.
- SIOPE introduced a new website for the Clinical Research Council to facilitate communication between its members.
- Several communication initiatives were carried out in 2016 to help increase the profile of SIOPE as the main reference for paediatric haematology-oncology in Europe, as well as the 10<sup>th</sup> anniversary marking the establishment of the SIOPE permanent secretariat in Brussels.



## Conclusion and the Next Steps

This report summarises the 2016 achievements of the projects and structures created to address the needs identified in the [SIOPE 'European Cancer Plan for Children and Adolescents'](#). Since the launch of this ambitious Plan, SIOPE managed to unite the European community around the same objectives, managing to raise awareness and generate action from all those who care for the future of childhood cancer patients and survivors.

During 2016, SIOPE focused on the next steps in the Plan's implementation and made remarkable progresses carrying out several initiatives. Glancing through this report, keep in mind this is not a measuring stick to see which objectives are doing the best. It is simply a snapshot of our achievements in 2016.

This report demonstrates how we have moved the needle on specific items for each objective. We wish to reiterate that this is a 10-year plan with seven clearly defined objectives and we are working very hard to ensure that all the goals set for the next decade will be achieved. We would like to express our gratitude to all the SIOPE members and partners who essentially supported us in this endeavour and made possible what we have been able to achieve so far.

However, there is still much to do. SIOPE is currently seeking the financial support of charities, companies, foundations as well as European and national grants to fund the complete implementation of this Plan. With a stronger financial support, more quality research would be funded and, thus, allow a better knowledge of paediatric cancers' biology and genetics. This knowledge would be translated from bench to bedside into safer and more effective innovative treatments for young patients. Research would not only benefit patients, but it would also address the long-term consequences of cancer treatment and improve the quality of life of an increasing number of survivors. The Plan's initiative would also contribute to reduce the existing inequalities in the quality and accessibility of the paediatric oncology care and treatment across Europe, and to integrate the specific needs of teenagers and young adults into standard care.

We are proud of the achievements so far and remain committed to increasing the cure rate and the quality of survivorship for children and young people with cancer over the next ten years. The report on the achievements for year 2017 will be published in 2018.



SIOPE Europe  
Avenue E. Mounier 83  
BE-1200 Brussels, Belgium  
Tel: +32 2 775 02 12  
Fax: +32 2 775 02 00  
[www.siope.eu](http://www.siope.eu)

**For all the additional information, please contact: [office@siope.eu](mailto:office@siope.eu)**