Title: SIOP Strategy 2021 – 2025: Cure for More, Care for All

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The International Society for Paediatric Oncology (SIOP) is the only global multidisciplinary society entirely devoted to paediatric and adolescent cancers. Since the publication of our last strategic review in 2015, SIOP's membership has grown to unite over 2,600 multi-disciplinary healthcare professionals and researchers working on paediatric cancers worldwide. The community shares a strong common purpose: to increase survival rates, to improve quality of survival and to ensure care for all. Developed through a highly consultative, collaborative process throughout 2019-20 and approved by the membership in October 2020, the SIOP Strategy 2021-2025 aims to provide a comprehensive framework to support targeted action in line with the joint vision of our community, while enabling full adaptation in local contexts across the globe.

We re-visited our Vision statement, that "No child should die of cancer", and agreed to retain it as our aspirational target, qualifying it with the more immediately achievable target of "Cure for more, Care for All". We have reconstructed our Mission statement as a set of activities that SIOP can provide or lead on (Fig. 1). These are spelt out in more detail under five main strategic goals.

Background to SIOP's strategic review

Building on the progress made against the development goals for SIOP articulated in 2014-16,¹ this new strategic review was initiated prior to the COVID-19 pandemic as the focus of a Board retreat in June 2019. It was finalized in June 2020 and for presentation to the membership at the Annual Business meeting, Oct 2020. Key developments and evidence to be considered in the development of the new strategy included:

- The rising importance of cancer across all ages and globally in the non-communicable disease (NCD) agenda as a cause of premature mortality and morbidity in survivors. Cancer is the principal cause of death in children in high income countries (HICs) and many middle-income countries (MICs). Individual types of paediatric cancer are rare but collectively, cancer in children and adolescents affect 1 in 430 children by their 15th birthday and 1 in 320 by their 19th birthday. Childhood cancer comprises between 0.5%-6% of all cancers in a population according to the age structure of that population and prevalence of certain predisposing infectious agents.²
- The need for specific approaches to cancer control in children and adolescents. Paediatric cancers have a very different biological basis from that of most adult cancers; their aetiological factors are largely genetic rather than environmental or life-style factors, hence opportunities for prevention are limited. Successful treatment requires a specialist workforce trained in the specificities of cancer in children and adolescents. However, there is a real shortage of capacity of both suitably trained workforce and appropriate facilities to treat all of the children and young people with cancer in the world, with particularly large gaps in lower middle-income countries (LMICs).
- The high curability of paediatric cancers, when accurate diagnosis, risk stratification and appropriate therapy and support is provided. More specifically, the 5-year survival for children and adolescents with cancer in many HICs is greater than 80%. However, only 10% of the world's children live in HICs. In contrast, in LMICs where 90% of the world's children reside, the reported 5-year survival

¹ "SOCIETY NEWS AND VIEWS International Society of Pediatric Oncology (SIOP): Developmental Goals 2014–2016: Communication Update," Pediatr Blood Cancer 2015; 62:1117–1118.

² Estimates derived from Steliarova-Foucher et al. International incidence of childhood cancer, 2001-2010. Lancet Oncol. 2017.

ranges from <10% to $^{\sim}60\%$ at a population level, with many countries having no national statistics available.³

Childhood cancer outcomes are influenced by determinants that range from available expertise and resources, health services delivery and international policy. The SIOP community is uniquely positioned to foster enabling conditions for optimizing the rate and quality of cure across all resource-settings.

High levels of participation in national and international collaborative clinical trials have underpinned the advances seen in HICs over many decades. Indeed, such participation may prove lifesaving for some children and adolescents with relapsed malignancies or in treatment failure. This is the reason that the SIOP Board of Directors has agreed to support the "big, goal":4 the of hairy, audacious SIOP for Advancing Research Capacity for Pediatric Cancer Clinical Trials (PARC Program), This programme operationalizes Goal 2 of the SIOP Strategy and aims to double the cure rate of children with cancer by 2030 by bolstering pediatric oncology clinical research infrastructure in MICs and LICs. This programme is in its early stages of development and requires SIOP to mobilise a complex web of interested stakeholders to achieve sufficient resourcing to make an impact.

Global economic stability has come under threat due to the Covid-19 pandemic in 2020 and 2021. National budgets have faced high demand to resource the health emergency response and sustain citizens' livelihoods. Recognising the importance of these immediate priorities, SIOP will make efforts to secure continued support for the childhood cancer sector to avoid stalling life-saving progress.

Public anxiety and distancing due to the Covid-19 pandemic mean a surge in delayed diagnoses is widely anticipated. Treatment interruption and abandonment are other potential consequences. Building on its rapid response,⁵ collecting information and providing further guidance to members will be another key orientation for SIOP. Our partnership with St. Jude Global Program to create the global registry⁶ and resource centre has already led to several useful outputs to the community.⁷ From a business continuity perspective, the impact on

³ Estimates derived from Atun et al, "Sustainable care for children with cancer: a Lancet Oncology Commission," Lancet Oncol 2020 Apr; 21(4):e185-e224, https://pubmed.ncbi.nlm.nih.gov/32240612/, DOI: 10.1016/S1470-2045(20)30022-X and Lam et al, "Science and health for all children with cancer," Science, 2019, https://pubmed.ncbi.nlm.nih.gov/30872518/, DOI: 10.1126/science.aaw4892

⁴ The big, hairy, audacious goal (BHAG) is a term coined by Jim Collins in his book "Build to Last". For more info, see https://www.jimcollins.com/concepts/bhag.html.

⁵ Bouffet E et al., "Early advice on managing children with cancer during the COVID-19 pandemic and a call for sharing experiences," Pediatr Blood Cancer. 2020 Jul;67(7):e28327. doi: 10.1002/pbc.28327. Epub 2020 Apr 24, https://pubmed.ncbi.nlm.nih.gov/32239747/, And Sullivan M et al., "The COVID-19 pandemic: A rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global," Pediatr Blood Cancer. 2020 Jul;67(7):e28409. doi: 10.1002/pbc.28409. Epub 2020 May 13, https://pubmed.ncbi.nlm.nih.gov/32400924/.

⁶ https://global.stjude.org/en-us/global-covid-19-observatory-and-resource-center-for-childhood-cancer.html

⁷ Moreira D et al, "The Global COVID-19 Observatory and Resource Center for Childhood Cancer: A response for the pediatric oncology community by SIOP and St. Jude Global," Pediatr Blood Cancer. 2021 May;68(5):e28962. doi: 10.1002/pbc.28962. Epub 2021 Feb 24., https://pubmed.ncbi.nlm.nih.gov/33629507/; Graetz D et al., "Global effect of the COVID-19 pandemic on paediatric cancer care: a cross-sectional study," Lancet Child Adolesc Health. 2021 May;5(5):332-340. doi: 10.1016/S2352-4642(21)00031-6. Epub 2021 Mar 4, https://pubmed.ncbi.nlm.nih.gov/33675698/; Mukkada S et al., "Global characteristics and outcomes of SARS-CoV-2 infection in children and adolescents with cancer (GRCCC): a cohort study," Lancet Oncol. 2021 Oct;22(10):1416-1426. doi: 10.1016/S1470-2045(21)00454-X. Epub 2021 Aug 26, https://pubmed.ncbi.nlm.nih.gov/34454651/; and Pritchard-Jones K et al., "The threat of the COVID-19 pandemic on reversing global life-saving gains in the survival of childhood cancer: a call for collaborative action from SIOP, IPSO, PROS, WCC, CCI, St Jude Global, UICC and WHPCA," Ecancermedicalscience. 2021 Feb 15;15:1187. doi: 10.3332/ecancer.2021.1187. eCollection 2021, https://pubmed.ncbi.nlm.nih.gov/33777180/.

international travel and large gatherings requires contingency planning and an exploration of alternative formats for educational events and governance meetings.

The World Health Organization Global Initiative for Childhood Cancer (GICC)⁸ is proving to be a game-changer by focusing the world's attention and resources on childhood cancer but requires sustained commitment and support from national governments. SIOP and its members can play a key role in promoting the GICC in their respective settings. The ultimate hope is that paediatric cancer is included in national health strategies and international development programmes, which can pave the way for dedicated budget allocation, implementation, and improved outcomes. Through its advocacy work, SIOP collaborates closely also with the Childhood Cancer International, the Union for International Cancer Control, our discipline-specific sister societies (Paediatric Radiation Oncology Society, International Society of Paediatric Surgical Oncology, Paediatric Psycho-Oncology Society and many others).

Strategic Goals

SIOP has identified the following five Strategic Goals that will help deliver its mission and vision in the coming five years (Fig 1):

Goal 1: Advocating Globally for Children and Adolescents with Cancer

Decision-makers are faced with multiple priorities for resource allocation in health and research. It is thus crucial that authorities and stakeholders influencing them are aware of childhood cancer and its specificities, the associated health loss and socio-economic burden, the potential to improve outcomes, and the means to do so. SIOP advocacy will foster the recognition of childhood cancer as an urgent priority, encourage universal healthcare, strive to translate increased awareness into specific initiatives and the inclusion of childhood cancer in health/cancer and research strategies, and emphasise the importance of concertation with childhood cancer professionals and patient, survivor and parents groups across the policy cycle from the local to the international level. To achieve this, SIOP will seek to consolidate its position as an important global stakeholder of reference for all issues pertaining to childhood and adolescent cancer.

Goal 2: Promoting Research to Improve Outcomes for Patients

Research drives the progress towards achieving our aims to improve cure rates and decrease short- and long-term toxicities of childhood cancer worldwide. To achieve this goal, SIOP will support research efforts throughout the Society, recognising excellence through awards and prize lectures, catalysing international networking and collaboration and advocating for meaningful involvement of patients and their families in the design and conduct of research projects globally. The flagship program under Goal 2 is the Programme for Advancing Research Capacity for Pediatric Cancer Clinical Trials (PARC Programme).

Goal 3: Providing Education and Training

SIOP members value the Society for its convening power (e.g. Annual Congress, periodic webinars), its reputation as a neutral expert professional voice as well as for its ability to create

⁸ https://www.who.int/publications/m/item/global-initiative-for-childhood-cancer

and disseminate knowledge that is important to the members' continued learning and professional growth. To achieve this goal, the Society will produce and disseminate information on 'state of the art' practice, key topics and emerging issues and creating and promoting opportunities for training and education, including online courses.

Goal 4: Increasing Membership and Engagement

SIOP serves its members in multiple ways: through building a sense of community, convening diverse stakeholders and partners, knowledge management, advocating, facilitating and learning, and by providing members with the resources, linkages and information that they need to conduct their work on paediatric oncology. The achievements of the Society are the collective achievements of its members. To achieve this goal, SIOP will study the membership trends over time; broaden and diversify the membership, and create more opportunities for programmatic engagement of members.

Goal 5: Strengthen and Expand Strategic Partnerships

SIOP is recognized as a global network of professionals knowledgeable about the needs of children and adolescents with cancer and the solutions for improving survival rates and quality of care. SIOP will strengthen its partnerships with organisations that share SIOP's vision to add value to mutually aligned or joint projects and to avoid duplication of efforts. To achieve this goal, SIOP will work with the WHO, parents and survivors; develop partnerships with childhood cancer health providers, donors and industry. In particular, the PARC Programme, which is a key component of this goal area, requires close collaboration and support from partners in order to achieve its targets and secure resources.

Cross-Cutting Themes

To support the implementation of the five goals, activities across several cross-cutting themes will be carried out.

Congress Development

Recognizing the pivotal role that the Congress plays within SIOP and the pressure that the Covid-19 pandemic has imposed on in-person gatherings, SIOP will seek to introduce innovations in the organization and delivery of the Annual Congress. To this end, SIOP has created a Congress Development Committee. This will research and offer members new means of interactions, networking, learning and knowledge-sharing during the Congress and aims to retain an on-line participation option in future hybrid Congress formats.

Brand & Communications

The SIOP brand is synonymous with high-quality science and strong member collaboration on paediatric oncology. In the coming 5 years, SIOP will continue maintaining a strong brand recognition. In addition to brand strategy, SIOP will develop a communications strategy that harnesses all forms of communications, including social media and other innovative methods and language.

Governance

At SIOP, governance means having systems and processes in place to ensure the overall direction, integrity, effectiveness, efficiency, supervision, transparency and accountability of the society. To this end, the SIOP Governance Committee will review the current governance against an established framework to produce a governance "audit" and draft recommendations for improvements.

SIOP Volunteers as the Driving Force and Engines of Excellence

SIOP initiatives depend almost exclusively on members' voluntary contributions of time and effort. Volunteers are the driving engines of SIOP's programmatic work. To advance and further strengthen this area of work, SIOP will appoint a Volunteer Engagement Focal Point and develop a Volunteer Engagement Plan, which addresses issues such as strategies for generating volunteer interest in SIOP initiatives, training and development, succession, evaluation, recognition etc.

Secretariat Staffing & Organization

With an ambitious Strategy for the 2021-2025 period, SIOP needs to increase its internal capacity to be able to deliver on its Strategic Goals. To this end, the SIOP Board will work to ensure the proper staffing, management, supervision, professional development and retention of the SIOP Secretariat.

Finances

The SIOP Board is committed to ensuring the financial health and strength of SIOP. To achieve this, a Finance Committee has been established with the goal of developing an income generation plan, financial reserves policy and a long term financial strategy.

SIOP in 2025: What Success Will Look Like

For the children and young people with cancer, success means that more are diagnosed early and accurately, with better access to appropriate treatment and care so that survival rates and quality of survival both improve. This can only be achieved by expanding the professional workforce capable of delivering this care and supporting their education, training and collaborative research efforts. To this end, success for SIOP means that SIOP is:

- a globally-recognised network with multidisciplinary expertise in childhood and adolescent cancer
- a reliable source of timely information on childhood cancer services and research and an important global advocate.
- an active facilitator of collaborative clinical and translational research among its members, to address unmet clinical needs in both HICs and LMICs.
- a vibrant society of strongly committed members, contributing to programs and activities.

How Can You Engage with SIOP?

SIOP encourages all professionals interested in paediatric oncology to join the Society. SIOP is open to all of you interested in or working in paediatric oncology. We encourage you to join our global community dedicated to our strong mission to provide Cure for More, Care for All. Here are a few ways of engagement:

- <u>Become a Member!</u> Join the 2,600-strong global network to help you grow professionally. Benefits include access to PBC and much more.
- Contribute to our Programs Join a SIOP Network or Working Group! SIOP offers many program areas of interest; from nursing to psychosocial support, from LIC/LMIC work to new medicines, SIOP has a lot to offer you. Explore the thematic networks and working groups to find and join the ones that interest you. Contact info@siop-online.org for more guidance.
- Amplify our messages through social media! Follow us on social media and help us spread the SIOP messages.

• Join the <u>2022 Annual Congress!</u> Learn the latest advances in the field of pediatric oncology, share your research and network with fellow members. Abstract submission for the 2022 Congress will open in spring 2022.

For more information, please contact info@siop-online.org. We are happy to hear from you!

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Figure 1: Vision, Mission and Strategic Goals