

Terms of Reference (TOR)



Survivorship Network

Purpose

Five-year overall survival rates in children with cancer exceed 80% in high-resource settings. While outcomes are more modest in lower-resource settings, they are anticipated to improve as a result of ongoing global initiatives. In view of the anticipated rise in childhood cancer survivors, addressing global paediatric cancer survivorship is a priority. Survivors of childhood cancer are at risk of chronic health conditions, organ dysfunction, cognitive and reproductive health concerns, subsequent neoplasms, and long-term financial and psychosocial issues, necessitating specialized and focused care.

Survivorship care is an underserved area in large parts of the world, with challenges in providing risk-based care and rehabilitation. Barring a few exceptions, relatively little research has been published about late effects or survivorship care from LMICs. There are multiple ongoing global initiatives and platforms, which address the social, psychological and life-rehabilitation issues. However, there is a felt need to have within SIOP, a platform for discussing, promoting and collaborating on the medical aspects of late effects, survivorship, and long-term follow-up. Such a network would address relevant issues across all income groups and help develop feasible and sustainable survivorship programs across the world.

Scope

The SIOP Survivorship Network aims to build a global network of interested healthcare professionals and foster the development of resource-adapted, sustainable survivorship care across all settings. The Network will align with SIOP Strategic goals 1, 2, 3 and 5 by promoting global awareness on survivorship, providing easy access to information about long-term follow-up guidelines, providing mentorship, conducting webinars and other educational initiatives, fostering global survivorship research, establishing collaborations and increasing the representation of survivorship research in the SIOP Annual Congress.

Authority

Decisions about the operations and activities of the Network are taken by the Co-Chairs of the Network. Whenever needed, the Co-Chairs may consult the SIOP Board of Directors and/or the SIOP Secretariat.

Membership

The SIOP Survivorship Network is open to any member who is interested in Survivorship in childhood cancer. Members can join at any time by going to SIOP CONNECT and clicking the JOIN button for this Network. All Network members must be SIOP members in good standing, i.e. with SIOP membership fees paid for the current year, in order to join this Network.

Membership of the SIOP Survivorship Network is multidisciplinary and includes representation from physicians, nursing, allied health professionals, young professionals etc. There is no geographic restriction for members: members from any country are encouraged to join.

This Network relies on active participation of its members to achieve effective outcomes. Members are strongly encouraged to step forward with offers to give short online lectures, discuss recent publications or research in survivorship, or to organize other activities that may be of interest to the Network members.

The Network Co-Chairs do not keep an external list of members: only those who have paid their SIOP annual membership dues and opted into the Network (via SIOP CONNECT) are considered to be Network members. The SIOP CONNECT platform for email communication to the Network members reaches only those people who have paid their SIOP membership dues for the current year.

Co-Chairs and Steering Group (SG)

The Network is led by two Co-Chairs supported by a Steering Group (SG), who are all SIOP members in good standing with membership fees paid for the current membership year. Any SIOP member in good standing can nominate or self-nominate for the Co-Chair positions. The Co-Chair positions should be staggered to allow continuity of know-how and workstreams.

The Co-Chairs have a 3-year term and are expected to dedicate at least 6 hours of work towards the Network each month. A 2nd term of 3 years may be possible upon re-election. The Co-Chair positions are not SIOP Board-level positions.

The SG consists of 7 SIOP members in good standing: 2 of the 7 Steering Group members are Co-Chairs, one SG member out of the 7 is assigned by the Young SIOP Network, and remaining 4 SG members are elected. Any SIOP member interested in leadership for advancing Survivorship in paediatric oncology can nominate themselves or be nominated for a SG position. SG members are expected to allocate at least 4 hours each month towards the work of the Network, including attending meetings and working offline on tasks assigned.

The SG members have a 3-year term. A 2nd term of 3 years may be possible upon re-election. To achieve SG term staggering, the first cohort of SG members will have 3 members appointed for 2 years and 4 members appointed for 3 years.

In the unlikely event that a SG member becomes unresponsive, the Co-Chairs will write to the SG member about their participation (attend online meeting calls, answer emails, etc.). If no response, or an unsatisfactory response, is received, the Co-Chairs will inform the SG and with the SG approval, the SG member will be informed that their term has ended, and the seat will be filled by a special election.

Any vacated seats (Co-Chair or Steering Group member) will be filled through an election process managed by the SIOP Secretariat. Any SIOP Survivorship Network member in good standing can vote for a Co-Chair/ Steering Group candidate.

If nominations yield more than 3 candidates for any Co-Chair or SG seat, the SIOP Survivorship Network Steering Group will narrow down the slate of candidates to no more than 3 and put those forward for voting. If there is open Co-Chair and SG position, one candidate can only apply for 1 of those 2 positions.

All Co-Chairs and SG members should maintain their SIOP membership valid during their years of service to the SIOP Survivorship Network. Membership year at SIOP runs from January 1 to December 31.

INAUGURAL SG/Co-Chair Convening: For convening the inaugural team of 5 Steering Group members and 2 Co-Chairs for this Network, a Selection Team consisting of 3 members of SIOP Board of Directors (President, Secretary-General and one more Board member) will review all nominations/self-nominations for Co-Chairs/SG members and select the 7 inaugural members (1 SG member is elected from nominations coming from YSN as a YSN representative to this Network's SG). Thereafter, when the terms of the position-holders end or when a position is vacated, a regular nomination and election process will be carried out as per this TOR.

Meeting Arrangements

The Network Co-Chairs organize periodic meetings for the Network, which are advertised on the Network's calendar on SIOP CONNECT and via email through SIOP CONNECT to its members. Network Co-Chairs may also communicate relevant information and activities to the whole SIOP community via the SIOP Weekly Bulletin.

SIOP Secretariat provides periodic training to the Network Co-Chairs on the use and functionality of SIOP CONNECT. Network Co-Chairs can request such training by contacting programs@siop-online.org.

Reporting

The Network Co-Chairs report to the SIOP Board of Directors. The Network Steering Group members report to the Network Co-Chairs.

The Network Co-Chairs will contribute content to the SIOP Annual Report. Occasionally, SIOP Secretariat may ask for ad-hoc reports on the work of the WG for the needs of SIOP Secretariat or the Senior Management Committee. The SIOP Secretariat summarizes and sends out monthly program updates covering all Networks' accomplishment that month.

Deliverables

The Network organizes and delivers activities for its members on topics and issues related to Survivorship in childhood cancer. The Network offers **a minimum of three non-Congress activities for its members each year**. These could be educational webinars, learning sessions, case discussions, research outcomes sharing, collaborative research initiatives, collaborations with internal and/or external partners, surveys, Journal studies, presentation of recent research findings etc. Network activities are advertised via email to all Network members. For any activities that require SIOP Secretariat support, please contact programs@siop-online.org.

Any Network activities or sessions offered during the SIOP Annual Congress would need to be organized according to the processes, timelines and approvals led by the SIOP Scientific Committee. Please contact the Scientific Chair or CEO for questions and support.

All Network activities are in line with the five goals of the SIOP Strategy (2021-2025):

- Goal 1: Advocating Globally for Children and Adolescents and Young Adults with Cancer
- Goal 2: Promoting Research to Improve Outcomes for Patients
- Goal 3: Providing Education and Training
- Goal 4: Increasing Membership and Engagement

- Goal 5: Strengthen and Expand Strategic Partnerships

In particular, the Network will develop and offer activities for its members in the following areas:

1. Promoting global awareness on survivorship after childhood cancer
2. Providing easy access to information about long-term follow-up guidelines applicable across all resource settings
3. Providing mentorship in establishing and expanding survivorship clinics to interested SIOP members.
4. Conducting webinars and other educational initiatives on the practical aspects of establishing and expanding survivorship care
5. Fostering global survivorship research across all resource settings.
6. Collaborating with international groups involved in survivorship care and research, as well as related groups with SIOP Networks and Working Groups including SIOP PPO Network, SIOP Nursing Network and Supportive Care Networks.
7. Increasing the representation of survivorship research in the SIOP Annual Congress, and eventually developing a survivorship track

Website and SIOP CONNECT

The Co-Chairs are responsible for keeping information on the Network's public webpage up-to-date. Similarly, they are responsible for updating the Network space on SIOP CONNECT. At a minimum, once a year at the request of the SIOP Secretariat, the Network Co-Chairs review and update the existing information.

The Network Co-Chairs are strongly encouraged to use all functionality of SIOP CONNECT to engage with their Network members; namely, group discussion, file library, polls, discussion board, message system, email system, photo gallery etc.

Review of Network Performance

The SIOP Governance Committee, on behalf of the SIOP Board of Directors, conducts periodic reviews (once a year) of the effectiveness and need for all individual Networks. On the recommendation of the Governance Committee, the Board of Directors may dissolve a Network if its remit has been fulfilled or if there is no longer interest and participation from the Network membership.

Review

This Terms of Reference document will be updated annually based on the feedback from the Network members, Co-Chairs and SIOP Secretariat and the accomplishment of priority outputs.

Next review: August 2025

TOR Completed by:

SIOP Secretariat