

Terms of Reference (TOR)

Epidemiology and Outcomes Network



Purpose

Epidemiology is essential for identifying patterns of health and disease, understanding causes and risk factors, and informing public health policies and interventions to improve the health of communities worldwide. Indeed, epidemiologic investigation of childhood cancer incidence, etiology, and outcomes has been critical to gains in risk prediction and early detection, as well as improvements in survivorship care.

In recent years, there is increasing interest in use of routine health care data for research. For rare diseases such as cancers in children and young people, this offers a huge potential to improve understanding of patient outcomes according to more detailed clinical and genetic phenotypes, tumour biomarkers, treatments received etc. This type of 'data-driven' research requires building stronger relationships between clinicians, epidemiologists, cancer registries, data scientists and involving patients and parents in research design, implementation and communication.

Currently over 600 SIOP members have indicated an interest or expertise in epidemiology. The SIOP Epidemiology and Outcomes Network provides programmatic activities and a forum for its members to network, establish collaborations, and share ongoing research in epidemiology and outcomes, and encourage greater collaboration with clinical researchers.

Scope

The role of the SIOP Epidemiology and Outcomes Network in the international pediatric oncology community is particularly valuable. Given the rarity of childhood cancers, international collaboration is crucial to sufficiently power epidemiologic and data-driven studies, demonstrate reproducibility of results, and generate hypotheses on factors underlying observed worldwide disparities in incidence, access to care and outcomes. Additionally, it is widely recognized that lack of diverse representation in genetic epidemiology studies has led to poor generalizability of results. Therefore it is imperative to promote international collaboration so that all children worldwide may benefit from the insights gained through epidemiologic and data-driven research. The Network aims to foster collaboration, facilitate and form mentorship relationships for young investigators, and establish formal opportunities for networking, career development, and professional support.

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 SIOEP Epidemiology and Outcomes Network is open to any member who is interested in epidemiology and outcomes in childhood cancer. Members can join at any time by going to SIOEP CONNECT and clicking the JOIN button for this Network. All Network members must be SIOEP members in good standing, i.e. with SIOEP membership fees paid for the current year, in order to join this Network. Membership of the SIOEP Epidemiology and Outcomes 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 epidemiology and outcomes, 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 SIOEP annual membership dues and opted into the Network (via SIOEP CONNECT) are considered to be Network members. The SIOEP CONNECT platform for email communication to the Network members reaches only those people who have paid their SIOEP 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, who are all SIOEP members in good standing with membership fees paid for the current membership year. Any SIOEP 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 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 a Board-level position.

The SG consists of 7 SIOEP 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 SIOEP Network, and remaining 4 SG members are elected. Any SIOEP member interested in advancing epidemiology and outcomes in paediatric oncology leadership can nominate themselves or be nominated for a SG position. SG members are expected to allocate 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 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 elections process managed by the SIOEP Secretariat. Any SIOEP Epidemiology and Outcomes 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 SIOEP Epidemiology and Outcomes 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 SIOEP membership valid during their years of service to the SIOEP Epidemiology and Outcomes Network.

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 SIOEP 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 nominations and elections processed 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 SIOEP CONNECT and via email to its members. Network Co-Chairs may also communicate relevant information and activities to the whole SIOEP community via the SIOEP Weekly Bulletin.

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

Reporting

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

The Network Co-Chairs will contribute content to the SIOEP Annual Report. Occasionally, SIOEP Secretariat may ask for ad-hoc reports on the work of the WG for the needs of SIOEP Secretariat or the Senior Management Committee.

Deliverables

The Network organizes and delivers activities for its members on topics and issues related to epidemiology and outcomes 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. For any activities that require SIOEP Secretariat support, please contact programs@siop-online.org.

Any Network activities or sessions offered during the SIOEP Annual Congress would need to be organized according to the processes, timelines and approvals led by the SIOEP 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 SIOEP 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. Input into SIOP Scientific Congresses:
 - a. To conduct surveys to inform the SIOP Scientific Committee about topics of interest and leading-edge research to consider for the Annual Congress and Continental SIOP Congresses, educational programmes and workshops. Surveys would cover SIOP members and non-SIOP researchers in relevant fields, with the latter reached through contacts of the network members.
 - b. To organise such workshops or educational sessions in/alongside an Annual Congress or Continental SIOP Congresses and/or to suggest these topics for inclusion in the main Congress programme(s) and to organise in conjunction with the relevant SIOP Congress Scientific Committee.
 - c. Submit epidemiology related abstracts and topic proposals each year
2. To actively recruit and connect more experts in this realm into SIOP to broaden membership. New members will join the Network via SIOP CONNECT.
3. At the request of the SIOP President, at specific venues/occasions, represent SIOP's professional expertise and experience in global efforts to harmonise or create new standards for data collection.
4. To produce white papers on important issues in the field (classical epidemiology; clinical outcomes research; data science etc) convening international experts to address key questions of relevance to a global audience
5. To identify suitable external funding opportunities and to motivate the network members to organise to lead or jointly write grant proposals that span more than one continental branch
6. To create a mentorship program where junior investigators are paired with mentors who can provide professional development advice, collaborate scientifically and advise on projects/grants the junior investigator would lead
7. To collaborate with existing major national or international organizations and projects (e.g. [CLIC](#), [Pediatric Cancer Data Commons](#), [NCI Childhood Cancer Data Initiative](#), [ChildGICR at IARC](#), and [many others](#)) large to conceive and be part of international collaborative research projects and joint grant submissions.

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 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: April 2025

TOR Completed by:

SIOP Secretariat