



**Terms of Reference (TOR)  
AYA Working Group  
Global Health Network**

DATE: march 18, 2024

**Working Group (WG) Name**

Adolescents and Young Adults (AYA) WG

**WG's Belonging (Network Name)**

This WG is a part of the SIOP Global Health Network (GHN).

**Purpose**

As childhood cancer survival has increased significantly in recent decades in low- and middle-income countries (LMIC), attention is starting to shift to adolescents and young adults (AYA: 15-39 years of age) with pediatric cancers, who are yet to be included in most twinning partnerships and nascent pediatric oncology programs in these countries.<sup>1</sup> Even though there are over 1 million new cancer diagnosis in AYA patients worldwide with the majority of these cases occurring in LMIC, global data on cancer care delivery in this age group is scarce.<sup>2</sup>

It is well documented in high-income countries (HIC) that the rates of survival for AYA do not approach that of younger patients for multiple cancer diagnoses for multiple reasons, including the scarcity of AYA-specific clinical trials, lack of access to appropriate care (diversion to adult oncology programs that lack expertise in pediatric cancers) and possible biological differences in tumors.<sup>3,4</sup> In HIC, the disparities in outcome is known as the “AYA Gap” and while not clearly documented in LMIC, a similar “gap” in these countries is likely and is beginning to be recognized globally.<sup>1-3,5-7</sup>

Therefore, The Global Health Network (GHN) AYA Working Group (WG) intends to explore the experience of AYA patients with cancer in LMIC and to determine how best to support them and the medical providers that treat them. The Global Health Network (GHN) AYA Working Group (WG) aims to develop and facilitate group efforts to address issues surrounding access, education, support, quality, and outcomes for adolescents and young adults with cancer.

The WG also works to foster multidisciplinary partnerships involving research, advocacy, capacity building and educational efforts to address adolescents and young adults with cancer in diverse settings.

**Scope**

The aim of the WG is to work globally to address the physical, emotional, psychosocial, and spiritual suffering of adolescents and young adults and their families associated with their cancer. This will be done through collaborative efforts between multidisciplinary partnerships and will address these issues in AYA patients specifically in both low-resourced and high-resourced settings.

## Authority

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

## Membership

The GHN AYA WG is open to members who are interested in improving care of AYA with cancer. Members can join at any time by going to SIOP CONNECT and clicking the JOIN button for this WG. One must be a SIOP member in good standing, i.e. with SIOP membership fees paid for the current year, in order to join this WG.

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

This WG 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 on AYA oncology care, or to organize other activities that may be of interest to the AYA WG members.

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

## Co-Chairs

1. This WG is led by two Co-Chairs who have 3-year terms.
2. Any SIOP members in good standing, with membership dues paid for the current year, may nominate themselves or be nominated by another member for the Co-Chair role. The SIOP Secretariat manages the process for nominations and elections.
3. The GHN Core Steering Group will narrow down the slate of Co-Chair candidates to no more than three candidates who will be put forward for a vote.
4. Only AYA WG members are able to vote in the elections.
5. A second 3-year term for the Co-Chairs is possible upon re-election. There is no automatic term extension for any position.
6. To ensure continuity of work, the next Co-Chair of the AYA WG will be identified at least six months before the end of the incumbent's mandate to facilitate a smooth leadership transition. The Co-Chair-Elect can start attending meetings of the WG as soon as he/she is identified.

## Meeting Arrangements

The WG Co-Chairs organize periodic meetings for the WG, which are advertised on the WG's calendar on SIOP CONNECT and via email to its members. WG 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 WG Co-Chairs on the use and functionality of SIOP CONNECT. WG Co-Chairs can request such trainings by contract [programs@siop-online.org](mailto:programs@siop-online.org).

## Reporting

Both WG Co-Chairs report to the GHN Co-Chairs.

The WG 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.

## Deliverables

The WG organized and delivers activities for its members on topics and issues related to AYA with cancer. The WG offers a minimum of three non-Congress activities each year for its members. These could be educational webinars, learning sessions, case discussions, collaborative research initiatives, collaborations with internal and/or external partners, surveys, Journal studies, presentation of recent research findings etc. For any activities that require SIOP Secretariat support, please contact [programs@siop-online.org](mailto:programs@siop-online.org).

Any WG activities or sessions offered during the SIOP Annual Congress 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.

The WG 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

## Website and SIOP CONNECT

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

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

## SIOP Bylaws

The Co-Chairs of the SIOP Global Health Network, to which this WG belongs, are expected to conduct annual reviews of the work and achievements of the WG in order to assess continued need for the existence of the WG. If the GHN Co-Chairs determine that this WG has not delivered any activities in the past six months, they may close down this WG. If the GHN Co-Chairs are unable or unwilling to close down a non-functioning WG, the SIOP Governance Committee will review the activities and may close down this WG.

## Review

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

Next review: March 2025

**TOR Completed by:**

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Tessie Laub, SIOP Secretariat

**References**

1. Ferrari A, Barr RD: International evolution in AYA oncology: Current status and future expectations. *Pediatr Blood Cancer* 64, 2017
2. Fidler MM, Gupta S, Soerjomataram I, et al: Cancer incidence and mortality among young adults aged 20-39 years worldwide in 2012: a population-based study. *Lancet Oncol* 18:1579-1589, 2017
3. Bleyer A, Ferrari A, Whelan J, et al: Global assessment of cancer incidence and survival in adolescents and young adults. *Pediatr Blood Cancer* 64, 2017
4. Lewis DR, Seibel NL, Smith AW, et al: Adolescent and young adult cancer survival. *J Natl Cancer Inst Monogr* 2014:228-35, 2014
5. Smith AW, Seibel NL, Lewis DR, et al: Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. *Cancer* 122:988-99, 2016
6. Curado MP, Pontes T, Guerra-Yi ME, et al: Leukemia mortality trends among children, adolescents, and young adults in Latin America. *Rev Panam Salud Publica* 29:96-102, 2011
7. Jaime-Perez JC, Padilla-Medina JR, Fernandez LT, et al: Outcomes of Adolescents and Young Adults With Acute Myeloid Leukemia Treated in a Single Latin American Center. *Clin Lymphoma Myeloma Leuk* 18:286-292, 2018