

SIOP PODC PATIENT, FAMILY AND STAKEHOLDER ENGAGEMENT TASK FORCE

The SIOP PODC Patient, Family and Stakeholder Engagement (PFSE) Task Force has been engaged in a research project to explore patient and parent/guardian engagement in low- and middle-income countries (LMIC) since 2018. An extensive literature review revealed only 4 articles on engagement during treatment from LMIC. High-income country pediatric oncology literature on engagement described forms of engagement the Task Force members thought did not necessarily reflect experiences in LMIC.

Professional qualitative researchers who were natives of the countries or region (and spoke local languages) conducted in-depth interviews and focus group discussions with recent (<2 years) and longer term (<5 years) childhood cancer survivors who were older adolescents or young adults and parents/caregivers of children treated for cancer in each country. The participating countries included: Mexico, El Salvador, Peru, Morocco, South Africa, Ethiopia, the Republic of Georgia, Iran, India, and Greece (Albanian family seeking care in Greece).

Data was collected throughout 2019 with the support of CCI-affiliated local foundations in many of the countries. All researchers, 2 pediatric oncologists, 1 local foundation member and 2 qualitative research nurses from SIOP came to a successful 5-day workshop to discuss findings just before the SIOP/CCI Congress in Lyon in October 2019. The most common theme across the data was communication in all forms (e.g., physician family/patient, parent and extended family, parent to child, and patient with physician).

A total of 6 abstracts have been accepted for presentation at the SIOP virtual Congress. Publications accepted, submitted or in development include: accepted: *Journal of Global Oncology* – Latin American parent/caregiver engagement; Submitted - CCI Newsletter, summary of project; Submitted - CCI Latin America only, summary of project in Spanish; Development – Latin American young survivor data; Development – invited paper for the Royal Anthropological Institute (London) – on study's methodological approach collaborating with CCI and local childhood cancer NGOs; Development – Iranian study findings; and Development – South African study findings.

We thank all CCI local foundations for their significant support and help identifying respondents. We are excited to share our findings with the SIOP and CCI communities in the hopes that we can improve the care of children/adolescents with cancer and their families in LMIC.