The impact of the SIOP Programme for advancing research capacity on global childhood cancer research

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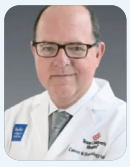
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Childhood cancer survival exceeds 80% in high-income countries (HICs) but remains far lower in many low- and middle-income countries (LMICs), where most affected children live and where little research occurs. Applying HIC protocols may lead to poorer outcomes in less well-resourced institutions, underscoring the need for context-specific evidence. Systemic barriers – fragile cooperative groups, underfunding, limited personnel, and regulatory complexity – further constrain LMIC research. To address this, the International Society of Paediatric Oncology (SIOP) launched the Programme for Advancing Research Capacity (PARC) in 2022, initially supporting cooperative groups in Latin America, Africa, and India. By strengthening infrastructure, training, and sustainability, PARC advances equitable paediatric oncology research and fosters long-term improvements in survival worldwide.

Addressing research disparities in childhood cancer

The survival gap

While significant progress has been made in childhood cancer, global outcomes remain markedly inequitable. In high-income countries (HICs), overall survival for children with cancer now exceeds 80% due to advancements made over the last 50 years through collaborative clinical trials and multidisciplinary care *(1)*. However, this success is not uniformly distributed. Childhood cancer survival rates in low- and middle-income countries (LMICs) are substantially lower, creating a major public health disparity. This profound imbalance is underscored by the paradox that over 90% of the world's children live in LMICs but less than 10% of childhood cancer research is conducted there *(2)*. This disproportionate allocation of research resources has resulted in a critical gap in locally relevant evidence, which is essential for developing, building up, and implementing effective treatment strategies.

The direct application of treatment protocols developed in HICs can lead to poorer outcomes in resource-limited settings *(3,4,5)*. A compelling example is the case of Burkitt lymphoma, where higher intensity chemotherapy regimens, which led to improved survival in HICs, resulted in unacceptable fatal toxicity when implemented in some LMICs *(4,5)*. This is often due to a higher proportion of patients presenting with advanced disease, as well as comorbidities such as malnutrition and chronic infections, and lower availability of intensive care support, which influence a patient's tolerance for intensive treatment. These outcomes highlight the critical need for context-adapted treatment protocols and the generation of local evidence for their clinical effectiveness *(6)*.

Systemic barriers to childhood cancer research

In LMICs, paediatric oncology research faces systemic barriers that go beyond clinical expertise. Because childhood cancers are rare, multicentre and often multinational collaborations are essential *(7)*. But cooperative groups in LMICs are typically fragile, underfunded, and unable to sustain long-term, high-quality research *(8,9)*. This financial instability is compounded

by a shortage of dedicated research personnel – such as study coordinators, research nurses, and data managers – leaving already overburdened clinicians to handle research tasks without institutional support or protected time *(8)*. As a result, research output remains limited, and fragile groups struggle to meet the demands of increasingly complex legal and regulatory requirements *(7)*. Together, these challenges make it extremely difficult to conduct rigorous clinical trials and generate the local evidence needed to improve outcomes for children with cancer (Table 1).

Table 1: PARC interventions to tackle the systemic challenges in paediatric oncology research in LMICs.

Systemic challenges in LMIC paediatric oncology research	PARC interventions
Organizational fragility Limited or no funding, fragile structures, and lack of legal status	**Legal formalization and governance** Grant support to formalize cooperative groups as legal civil society organizations
Lack of dedicated research personnel Work done by overstretched clinicians, no protected time or salary support	**Human resources and training** Funding for the addition of new personnel and training of key staff
Insufficient data management Lack of electronic data capture and secure platforms	**Data infrastructure** Supporting cooperative groups to develop their secure platforms for high-quality data capture
Lack of context-adapted evidence Direct application of HIC protocols leads to poor outcomes	**Enabling pragmatic protocols** Support for local groups to develop regionally-relevant clinical trials
Regulatory and administrative hurdles Complex laws for data and specimen sharing	**Legal and administrative expertise** Support for legal consultants and future consortium building to address shared barriers

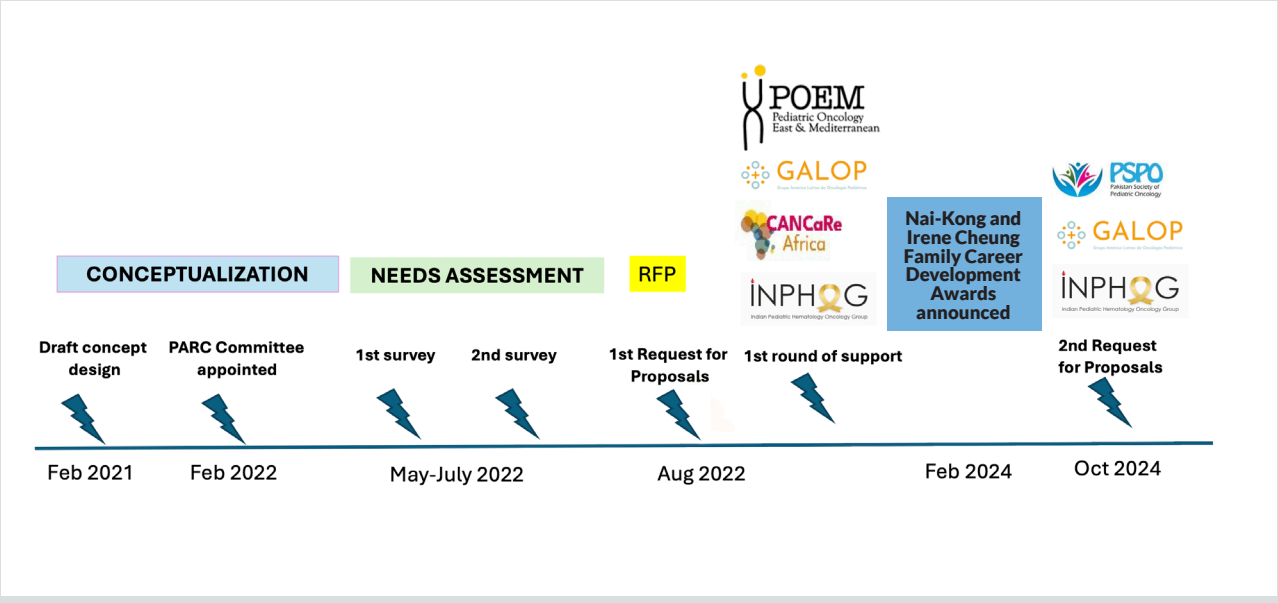
Abbreviations: LMIC, low- and middle-income countries; PARC, Programme for Advancing Research Capacity.

SIOP's support to childhood cancer research

A new model of intervention

In 2022, the International Society of Paediatric Oncology (SIOP) launched the Programme for Advancing Research Capacity (PARC) to address systemic challenges in paediatric oncology research in LMICs *(9)*. PARC's mission is to strengthen clinical research infrastructure so that local teams can generate evidence to guide treatment, improve care, and increase survival rates. This initiative aligns with SIOP's Strategic Plan, which identifies research support as a core pillar. Following a needs assessment in LMICs, PARC put this strategy into practice by supporting cooperative groups, enabling them to conduct research relevant to their settings (Figure 1). PARC is funded by Amazon, Foundation S, and private donors.

Figure 1: Timeline of PARC Programme development and groups funded – details available at https://siop-online.org/parc-committee/



The creation of PARC reflects the culmination of SIOP's long-standing commitment to its global membership. This evolution began in the 1990s with the Paediatric Oncology in Developing Countries programme, which helped bring professionals from LMICs into the Society and showcase their work. A milestone came in 2018, when SIOP was recognized as a non-state actor in official relations with the World Health Organization (WHO), strengthening its ability to advocate globally and contribute to the WHO Global Initiative for Childhood Cancer (GICC), where investment in cancer research infrastructure is a recommended priority action in the CUREALL implementation framework *(10)*. In 2022, WHO further emphasized the importance of building national research capacity through a key resolution *(11)*. Within this context, PARC represents the logical next step: moving beyond education and advocacy to provide direct funding and infrastructure support that will enable sustainable, locally driven paediatric oncology research (Figure 1).

The PARC Programme has three core objectives: 1) to enable SIOP members and partners to expand their clinical research capacity, 2) to advocate for the use of research to optimize outcomes, and 3) to mobilize resources for clinical research capacity development. Through grants, PARC supports international cooperative groups in Africa, Asia, and Latin America. A summary of the first three PARC-funded projects, implemented by cooperative groups, follows.

Latin American Group of Paediatric Oncology (GALOP)

GALOP made significant progress in strengthening its organizational and research foundations in a two-year-long project; it achieved legal recognition, enabling it to manage agreements, contracts, and funds effectively, while developing a standardized framework for data sharing and informed consent. It also built a member registry, recovered key documents from earlier initiatives, and created clear membership guidelines, consolidating its position as a formalized and collaborative research group. Furthermore, GALOP built research capacity by recruiting regional study coordinators, hiring a data manager, and securing a data platform. Extensive training strengthened technical expertise, while new Good Clinical Practice (GCP) certification requirements ensured research standards. Together, these actions not only exceeded initial goals but also created a scalable infrastructure for sustainable clinical research *(12,13)*.

GALOP also expanded its network, diversifying its membership, and launched new pragmatic clinical trials. Annual meetings bolstered collaboration, visibility, and partnerships across Latin America, while plans to integrate multidisciplinary specialists further enriched research capacity. Research networks for Wilms tumour and histiocytosis were consolidated, with new protocols designed, ethical approvals pursued, and registries developed to improve diagnostic and treatment practices. These initiatives, coupled with training and multidisciplinary collaboration, lay the groundwork for regionally adapted treatment protocols, ensuring GALOP's continued leadership in advancing paediatric oncology research and outcomes across Latin America.

Collaborative African Network for Childhood Cancer Care and Research (CANCaRe Africa)

CANCaRe Africa successfully strengthened research management and skills across its African research sites in a year-long project *(14)*. Dedicated local data managers were resourced at all nine centres, supported by a central data manager in Malawi who ensured quality oversight and mentorship. Regular monthly web meetings achieved high participation rates, focusing on data management and building research capacity. Training efforts exceeded expectations, with 230 Wilms tumour patients (vs 200 expected) and 400 SUCCOUR Phase 2 patients (vs 300 expected) enrolled, each with over 95% complete data, which is a remarkable achievement given the circumstances *(15–17)*. Continuous mentoring and monthly training sessions further improved data quality, coordination, and research skills across participating teams. All nine data managers and the CANCaRe Africa central data manager are still employed as data managers at their sites, demonstrating sustainability.

Progress on building grant development skills in core staff was more limited but still significant. Three proposals were submitted, including an ambitious and innovative strategy to reduce treatment abandonment *(18)*. Despite fewer regular online meetings than planned, a major in-person workshop in April 2023 gathered most site leaders and advisory members, allowing strategic discussions on ongoing projects, leadership transitions, and drafting seven planned publications, several of which are now published. These activities laid a solid foundation for future collaboration, capacity-building, and sustainability of paediatric oncology research in Africa.

The Indian Paediatric Haematology Oncology Group (INPHOG)

With limited funding, initial efforts built an ecosystem uniting centres for collaborative research studies, recruiting 13,182 children with cancer across 122 institutions in 24 INPHOG studies *(19)*. Formal PARC and other funding (2022–2024) has allowed INPHOG to make significant progress in strengthening paediatric oncology research capacity in India. A standardized paediatric cancer dataset was developed, and data capture software was piloted across multiple centres, with two studies already using the system. The Chennai population-based childhood cancer registry (PBCCR) and network of hospital-based childhood cancer registries (HBCCRs) study recruited

630 patients across 17 centres, and the national INPHOG HBCCR registry began enrolling patients after securing Clinical Trials Registry-India (CTRI) registration, with a goal of reaching 55 centres. Training for clinical research assistants (CRAs) was expanded: six full-time CRAs were initially hired and equipped, and capacity grew to 18; and CRA training workshops were held.

In parallel, interventional and retrospective studies advanced across six WHO Global Initiative for Childhood Cancer index cancers *(20,21)*. Recruitment was completed for 2,516 patients in the ICICLE 1 study on acute lymphoblastic leukaemia, followed by 421 patients enrolled in the ICICLE implementation study. Progress was also made in other cancers, with 700 patients recruited for Hodgkin lymphoma studies and more than 1,120 for retinoblastoma. New trials for Burkitt lymphoma and low-grade glioma are in preparation for 2025, while the Wilms tumour trial remains dependent on funding and regulatory approvals. In addition, a task force of civil society representatives was launched to ensure that patient and caregiver perspectives were integrated into research priorities and study design.

The PARC Programme has supported four more projects in the three continents, but at the time of publication of this article, activity information is not yet available. Furthermore, whenever possible, PARC collaborates on advocacy initiatives to promote the need for more paediatric cancer research in LMICs.

Fostering future leaders

The PARC Programme supports young researchers through the Nai-Kong and Irene Cheung Family Career Development Award. To date, two awards are helping nurture the next generation of researchers to establish successful patient-oriented research programmes with regional impact *(22)*.

The broader impact: Other capacity-building collaborations

The strategic principles of the PARC Programme are deeply aligned with the SIOP Strategic Plan and its emphasis on shepherding the research in childhood cancer. Furthermore, the Programme aligns with SIOP's broader mission to foster equitable "south-south partnerships" in settings where cooperative groups have not yet been established. This model emphasizes the prioritization of local needs, the cultivation of local expertise, and a commitment to truly equitable collaboration.

Strategic challenges and future directions

Navigating organizational and regulatory hurdles

The challenges faced by cooperative groups in LMICs are deeply ingrained and require sustained effort to overcome. As described above, insufficient funding, fragile organizational structures, and the lack of dedicated administrative and research personnel are persistent issues that PARC and its partners must continue to address. Furthermore, the complexity of legal and regulatory frameworks for data sharing and clinical trial implementation remains a significant hurdle. SIOP's own internal analysis of the PARC Programme's first funding cycle acknowledges these complexities.

A qualitative evaluation of the first four PARC Programme grants to cooperative groups is currently being conducted to understand the "complex, on-the-ground realities" of implementing capacity-building projects in LMICs. This study, which will involve semi-structured interviews and document reviews, aims to determine not just whether the grants met their goals, but "how and why those outcomes were – or weren't – achieved". This evaluation and the PARC Programme's commitment to learning demonstrate that SIOP recognizes that a simple, quantitative measure of success is insufficient. The Society is dedicated to understanding the nuanced, contextual factors that shape the implementation of cooperative groups' projects, and it will use these insights to guide future funding rounds and ensure that its approach remains grounded in the lived experiences of those involved.

Scaling impact and fostering sustainability

The future of the PARC Programme is focused on scaling the successes of the first funding cycle and building a truly sustainable research ecosystem.

In addition, a new major priority for the second round of PARC grants is the active engagement of "patients and civil society as active stakeholders in research." This will involve establishing formal partnerships with civil society organizations (CSOs), conducting educational workshops, and implementing communication strategies to foster collaboration and ensure research is aligned with patient needs. Crucially, the Programme will also help cooperative groups develop "long-term financial sustainability" by leveraging the fundraising experience of advocacy organizations. This shift from a focus on foundational infrastructure to an emphasis on building self-sustaining cooperative groups that are socially embedded and financially resilient is a testament to the Programme's long-term vision.

Conclusions and recommendations

PARC represents a significant and highly strategic intervention in the global effort to improve childhood cancer outcomes by fostering and strengthening sustainable regional clinical trial networks in LMICs. The Programme's unique approach, which targets the foundational infrastructure of research rather than individual trials, distinguishes it from conventional funding models. By providing grants for critical, often-overlooked

activities, such as legal formalization of cooperative groups, clinical research training and provision of human resources, as well as the development of data platforms, PARC is acting as a force multiplier, enabling the very existence of sustainable research in LMICs. ■

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Dr Trijn Israels is a paediatric oncologist with over 20 years of experience in Malawi and across sub-Saharan Africa. As co-chair of the SIOP Global Health Network, she led the development of adapted "SIOP PODC" treatment guidelines for resource-limited settings. Together with African colleagues, she initiated and led the Collaborative Wilms Africa Project and CANCaRe Africa, implementing these adapted treatment guidelines and pioneering multicentre prospective research in sub-Saharan Africa that has improved care and survival and generated over 60 publications. Her work focuses on pragmatic interventions, their implementation, and evaluation of impact, bridging clinical care, research, and capacity building to reduce childhood cancer mortality.

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