

The SIOP Global Mapping Programme: What we are learning and how it will benefit paediatric oncology care, support and families across Africa

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We present the state of care for children/adolescents with cancer across Africa and highlight key aspects of treatment from a parent's perspective. Survey data was collected from the Global Mapping Programme of the International Society of Paediatric Oncology (SIOP) made possible by support from the Sanofi Espoir Foundation. While previous surveys document global disparities in cancer care and resources, most do not identify available treatment services and facilities. This Programme data informs paediatric oncology clinicians, civil society organizations, families and other stakeholders of available treatment options and support whilst being mindful of the children/adolescents and families that we serve.

My daughter was diagnosed with acute lymphoblastic leukaemia when she was three years old. She was treated at four hospitals across London at various stages of her treatment. Fortunately, she has made a full recovery and has just finished her second year studying physics at university. As a member of the SIOP Global Mapping Programme Core Team, I have been well aware of published statistics highlighting the differences between care for children across the globe, and in particular what happens to children in resource-limited settings. However, there are similarities between her cancer journey and critical support resources that are offered to our family in England and those available in countries in Africa, and these are highlighted here.

(Neil Ranasinghe, parent of Anne)

Background

Childhood cancer is a growing burden in high-income countries (HIC) as well as low- and middle-income countries (LMIC) (1). Survival rates are up to 85% for most diseases in HIC, however this cure rate is not achieved across the rest of the world where >80% of children live (2). In general, children with cancer in HIC are diagnosed in an early stage of their disease, which improves their chance for cure. This is not the experience of most children in LMICs, where all levels of medical professionals may be unfamiliar with the symptoms of childhood cancer, referral processes are weak and tertiary-level care is limited to the capital or perhaps one other large city (3). Africa has a population of close to 1.34 billion (4), but as of 2021, only includes one HIC (Seychelles) and seven UMICs (5). As the rate of infectious disease decreases across Africa and other resource-limited settings, the noncommunicable disease burden (e.g., cancer) increases and is receiving global attention as reflected by government representatives at the WHO seventy-fourth World Health Assembly (6). Economic development in the recent past across Africa has been improving steadily despite contraction due to the 2020 global pandemic (7). Nevertheless, regional economic recovery (albeit variable) is expected as vaccines become available, and children/adolescents continue to receive treatment for cancer across this continent.

In 2018, SIOPI initiated a Global Mapping Programme for childhood cancer to determine available services and support for childhood cancer treatment especially in continents with many LMICs. The first continent surveyed was Africa since little documentation of the level of available treatment and family support services was available. The Global Mapping Programme provides an up-to-date picture of resources, staffing, and facility-level capacity to i) advocate for more resources; ii) enable collaboration to share data, and if appropriate, join clinical trials; and iii) produce an online map of childhood cancer treatment facilities. The survey methodology is described in detail by Geel et al., 2021 (8).

Key elements of successful childhood cancer programmes

This article reflects on childhood cancer across Africa as documented in the first phase of the SIOPI Global Mapping Programme. Here, we address access to and importance of key elements of childhood cancer care. The first author, parent of a survivor of childhood cancer, identified specific survey data to highlight disparities and commonalities in treatment in the United Kingdom compared to countries in Africa from a parent perspective. We hope the findings and commentary presented here provide a baseline portrait of achievements to date, as well as a roadmap for moving forward locally and

in collaboration with global efforts, e.g., the WHO Global Initiative for Childhood Cancer (GICC). The GICC aims to improve childhood survival to 60% by 2030 worldwide (1). Selected key elements of childhood cancer care presented here are essential to achieving this goal and making a difference in the lives of children/adolescents with cancer in LMICs. Current disparities and gaps in childhood cancer care must be documented to be successfully eliminated – this is the purpose of the SIOPI Global Mapping Programme.

What happens if there is no or limited childhood cancer treatment in your country?

Neil Ranasinghe, parent of a survivor of childhood leukaemia, and member of the SIOPI Global Health Network, and SIOPI Global Mapping Programme Core Team member

African data from the SIOPI Global Mapping Programme showed a wide disparity in services and facilities available to children/adolescents with cancer and their families. Some hospitals are well equipped and offer chemotherapy, radiotherapy and specialised surgery, whilst others only provide basic cancer care. Some countries have no paediatric oncologists meaning that adequate cancer therapy is extremely difficult to provide.

There are countries with literally no facilities treating children/adolescents with cancer (9). In some cases, e.g., Eswatini, the children are sent to neighbouring South Africa for treatment, however, this is disruptive to the families' lives and leaves siblings and other family members at home who would normally serve as a support system for the child and parent.

Many childhood cancer care actions and treatments can be implemented at a national level in Africa and are not prohibitively expensive (10). Outcomes for children/adolescents with cancer across Africa will not improve without a well-trained paediatric oncology health workforce. Other factors that significantly improve outcomes includes appropriate medical imaging, universal health coverage, locally relevant research, cancer registries and support from non-governmental organizations (NGOs). The SIOPI Global Mapping Programme provides updated documentation of capacity in the region. The following addresses each of these elements of childhood cancer care, written by an African or international expert on the selected topic.

Access and importance of medical imaging for childhood cancer across Africa

Dr Joyce Balagadde Kambugu, Head of Paediatric Oncology, Uganda Cancer Institute

Limited access to imaging is one of several contributors to poor outcomes of childhood cancer in Africa. While this can be attributed to inadequate resource allocation to healthcare

Table 1: Major antibiotic resistance in Iran between 2013–2014 (WHO, 2014)

Payment of care in your setting at facility level	Responses			
	Fully subsidised by state/donors	Partially subsidised by state/donors	Paid for by the family of the patient	No answer
Answers	36 (33%)	39 (36%)	24 (22%)	10 (9%)

Note: Totals may not add up to 100% due to rounding.

in general especially noncommunicable diseases, under-appreciation of the essential role of imaging in treatment outcome should also be noted. Imaging is important at every step in the continuum of cancer management – detection, diagnosis, staging, treatment planning, assessment of treatment response and long-term follow up. Moreover, the authors of the *Lancet Commission on Imaging and Nuclear Medicine* (2021) showed significant cost saving advantages with good imaging services overall (11). On its own, purchase of expensive imaging equipment will not have the desired effect on cancer treatment outcome. There must be a robust maintenance plan for the equipment, continuous availability of consumables such as films, reagents etc., and skilled human resource to deliver the service holistically. Otherwise, the expensive equipment will sit in facilities unused.

The SIOG Global Mapping Programme in Africa showed significant disparities in access to imaging both between countries and within countries. Not surprisingly, for basic imaging, at least one respondent in 44 (94%) of 47 countries reported having access to X-Ray, and 45 (96%) have access to ultrasound. More advanced technologies (e.g., computed tomography) were only reported as available in 79% (37) of 47 countries. Still, at this point in Africa, models referred to in the *Lancet Commission on Imaging and Nuclear Medicine* suggest that the largest survival advantage may be brought about by scaling up access to conservative imaging rather than to newer modalities like PET.

Access and importance of universal health coverage

Lorna Renner, Associate Professor, Department of Child Health, University of Ghana

In order to achieve the target of the WHO GICC, countries will have to make all efforts to improve outcomes by, amongst other strategies, ensuring access to effective treatment and reducing treatment abandonment. The implementation of Universal Health Coverage (UHC), which should include childhood cancer care, would be an important approach to achieve this. According to the WHO, “Universal health coverage means that all people have access to the health services they need, when and where they need them, without financial hardship” (12).

Unfortunately, with regards to childhood cancer, this has not

been fully achieved in several LMICs. Evidence from the SIOG Global Mapping Programme undertaken in Africa showed that only a third of the respondents from 47 countries affirmed full treatment cover by the state or donors (see Table 1). Fifty-eight percent had partial cover or families having to pay solely out of pocket. This is a reality, for example, from personal experience in Ghana, families have to pay out of pocket to access life-saving treatment for their child who has cancer. Countries have committed to UHC but advocacy at the local level is still required for childhood cancer care to become a priority and for adequate health financing. There is strong evidence to support advocacy efforts showing the cost-effectiveness of childhood cancer treatment in LMIC globally and in Africa in particular (10,13,14).

Importance of active paediatric oncology clinical research programmes

Kathy Pritchard-Jones, President of SIOG, Professor of Paediatric Oncology, University College London (UCL) and Great Ormond Street Institute of Child Health, London, UK

It is widely accepted that improvements in childhood cancer survival rates go hand in hand with active participation in clinical research, including observational studies and registries (15-17). However, most of the evidence supporting ‘best practice’ treatment recommendations for children and young people with cancer living in resource-limited countries comes from research studies performed in HIC (18). Yet, there are many other determinants of outcomes in LMICs including treatment toxicity and abandonment, drug shortages, sub-optimal diagnostic facilities, poor access to specific treatments such as radiotherapy. Therefore, clinical research performed in LMICs, which deal with these context-specific issues and constraints, is essential to define the optimal therapeutic strategies to improve cure rates and decrease short- and long-term toxicities (19).

The SIOG Global Mapping Programme survey for Africa investigated the current status of clinical research activity across the continent, with 23 low-income countries (LIC), 23 lower-middle-income countries (L-MIC), 7 upper-middle-income countries (UMIC) and one HIC. It is encouraging that 31% (34/109 units) and 49% (23/47 countries) reported

having an active clinical research programme (24). The finding compares to 82% of 35 European countries reporting a national childhood cancer research society or network when surveyed by SIOP Europe in 2013 (16). LMICs offer a great potential for patient recruitment to observational studies, including those that define priority areas for intervention to improve survival rates and those that investigate tumour biology and genetics in the local population.

Units that are active in clinical research and cancer registration processes are more likely to generate local evidence on safety and efficacy of treatments used. When available, parents/caregivers should be offered the opportunity to have their child participate in relevant clinical trials and studies that aim to improve the optimal treatment for all children/adolescents with cancer. The best example on how information coming from LMICs could influence treatment worldwide comes from Hodgkin lymphoma. In the 1970s, it was treated with combined radiotherapy and chemotherapy in HICs. However, the lack of availability of radiotherapy in LMICs made it impossible to administer radiotherapy with chemotherapy to patients, and results later confirmed, that such combination regimens were unnecessary for many patients in all countries (20,21). Therefore, this is a two-way road in knowledge generation (22). Nevertheless, barriers to oncology clinical trials in LMICs have been well documented and calls for funding and capacity building are on-going (19,23-25).

Treatment of cancer in children and young people is constantly being refined and the best “standard of care” is widely recognized as inclusion in a clinical trial or study, even for newly diagnosed patients. Treatment protocol recommendations need to be regularly updated, consistent with the latest research findings. Optimal treatment should be widely encouraged by a national childhood cancer research network including across LMICs.

Importance of national cancer registry

Professor Alan Davidson, Head of the Paediatric Haematology-Oncology Service, Red Cross War Memorial Children's Hospital and the University of Cape Town, South Africa

It is estimated that 41% of Africa's population (26) are under 15 years. Based on northern hemisphere data (140/m/year), this means 77,000 new cases of paediatric cancer annually. Recent data on survival for childhood cancer in sub-Saharan Africa reveal some of the lowest survival rates in the world for malignancies that in HIC have good rates of cure, including retinoblastoma and Wilms tumour. A barrier to improving these outcomes is the lack of accurate, population-based data from LMICs on childhood cancer incidence, stage at diagnosis and survival (27).

According to *The Cancer Atlas*, only 5.3% of childhood cancer

in Africa is registered (compared to 66% in Europe and 97% in the United States) (28). Registries help to track the incidence of new cancers in childhood, assess the extent and severity of disease at diagnosis and evaluate outcomes. Hospital-based cancer registries contribute to patient care by providing accessible information on patients with cancer, the treatment received and the outcomes. Specialized registries collect and maintain data on particular types of cancer. Population-based cancer registries (PBCR) collect data on all new cases of cancer occurring in a well-defined population, usually a defined region or country, and the emphasis here is on epidemiology and public health (29). As the most important form of PBCR, National Cancer Registries provide an invaluable resource of information for policy planning and research (30). They will enable us to tackle inequalities in access to appropriate care, ultimately leading to earlier diagnosis, better management, and improved outcomes for children with cancer in Africa. In the SIOP Global Mapping Survey, responses were received from 47/54 African countries, and 25 of these reported having a national cancer registry.

Importance of national paediatric oncology societies

Dr Maria El Kababri, Assistant Professor, Department of Pediatric Hematology and Oncology, Children's Hospital, Rabat, Morocco

A paediatric oncology society is an association of all professionals working with children/adolescents with cancer (e.g., paediatric oncologists, surgeons, radiation oncologists, radiologists, pathologists, biologists, nurses, and researchers) dedicated to the prevention, screening, diagnosis, treatment, and follow-up of paediatric cancers. Its missions are:

- ➔ Develop recommendations on therapeutic prescriptions and the organisation of paediatric oncology care.
- ➔ Promote research at national and international level.
- ➔ Create a space for dialogue between the various actors in paediatric oncology and with the supervisory authorities.
- ➔ Contribute to the education and continuing training of professionals and the evaluation of practices.
- ➔ Participate in the information and support of parents of children/adolescents with cancer.

In Africa, the role of a national paediatric oncology society is essential in the development of paediatric oncology, especially if its action is focused on the specific problems of the continent's countries and other similar contexts: continuous training of personnel, facilitating access to care and essential drugs, early diagnosis of paediatric cancers, and follow-up of patients under treatment to prevent treatment abandonment and reduce mortality. In addition, these societies organize and coordinate multidisciplinary treatment networks for childhood cancers.

Table 2: National paediatric oncology societies data from 109 facilities across 47/54 African countries from SIOG Global Mapping programme

National paediatric oncology society	Responses			
	Answers (109 hospitals)	Have society 23 (21%)	Don't have one 11 (10%) 2 (2%)	Don't know 73 (67%)

Note: Totals may not add up to 100% due to rounding.

Table 3: Non-profit organizations data of 109 facilities across 47/54 African countries from SIOG Global Mapping programme

Non-profit organisations that support children with cancer treated at your hospital?	Responses				
	Number of non-profit organizations Answers (109 hospitals)	1 48 (44%)	2 or more 25 (23%)	None 4 (4%)	Don't know 3 (3%)

Note: Totals may not add up to 100% due to rounding.

These societies also play a social role by providing support to families of children with cancer through advocacy for the cause of children with cancer. They are major players in the implementation and development of the WHO GICC

The SIOG Global Mapping Programme showed that only 13 African countries have a dedicated society (see Table 2); eight dedicated to paediatric oncology (Algeria, Morocco, Tunisia, Cameroon, Congo, Egypt, Nigeria, South Africa) and five for general oncology (Benin, Kenya, Mauritius, Uganda, Tanzania). However, few of them actively communicate on social networks through a website or other communication tools. It is clear that the development of paediatric oncology societies in Africa should be encouraged as a driver for the development of the discipline in a country and as an essential partner for the implementation of the WHO global initiative.

It should be noted since the time of the survey, some countries (e.g., Ghana) have formed a national paediatric oncology professional society as part of their activities to focus the country to implement the WHO GICC.

Importance of non-profit organisations (NGOs) for childhood cancer across Africa

Korede Akindede, Head of Programmes, The Dorcas Cancer Foundation, Lagos, Nigeria

Cancer is a bully. Much worse than the playground bully, cancer does not try to steal children’s lunch money. Cancer tries to steal their futures.

The role of NGOs cannot be over-emphasized when it comes to caring for cancer in Africa. Many of these NGOs such as The Dorcas Cancer Foundation have been at the forefront of awareness and advocacy mainly to ensure that children are brought in for treatment early, ultimately reducing both morbidities, and mortality related to cancer. Financial constraints and challenges have also been major obstacles. Cancer treatment is undeniably expensive, more so in a resource-poor setting like Nigeria and many other African

countries. NGOs are taking bold steps to bridge this financial gap between patient and treatment, by raising funds to pay for care, involving kind-hearted individuals, community, corporate organisations, and government in making sure that no child has to suffer cancer without access to care.

We know a cancer diagnosis is a toll beyond just the physical and financial, but also impacting the psycho-social aspects of the child’s life, confusing, and traumatic for patients and family alike. NGOs support this process and help these families get through by creating support group programmes.

Advocacy programmes in rural and urban communities, media awareness (TV and radio), and social media have also been effective tools used by NGOs across Africa region especially in Nigeria to combat childhood cancer. For the SIOG Global Mapping Programme data on African NGOs supporting childhood cancer, see Table 3.

Importance of the SIOG Global Mapping programme

Professor Eric Bouffet, past president of SIOG, Director of the Paediatric Neuro-Oncology Program, University of Toronto, Professor of Paediatrics Academic of Lyon, France

Many statements on the situation of paediatric oncology in the world start with the following comment: “Over 80% of children with cancer live in low and middle-income countries where survival rates are much lower than high-income countries”(24). However, although this statement is both heart-breaking and compelling, it is difficult to figure out the exact situation of these countries, the reasons for the poor outcomes and the solutions to improve survival. The SIOG Global Mapping of Africa has been an eye-opening experience, showing for example that in 15 countries, there was no trained paediatric oncologist or that the provision of chemotherapy was appropriate in only half of the continent (9). The collection of such detailed information offers many advantages, and in particular an opportunity for advocacy and targeted interventions aiming at improving training for the treating teams and access to care for patients.

Such work should not be limited to Africa. Further collection of information is critical in other continents where resources are limited, and a similar survey is ongoing in South and Central America and soon in South Asia. In addition, regular updates are needed to offer the most accurate information and measure progresses over time.

Conclusion: A better understanding, and providing help to families

The SIOP Global Mapping Programme has provided a much better understanding of how children/adolescents with cancer are treated across Africa. This is enabling collaboration with WHO GICC and assisting SIOP and local stakeholders including NGOs, to advocate for resources, equipment, and specialized paediatric oncology health workforce where it is needed most. The programme has highlighted that in many African countries, chemotherapy is not continuously available (9), which allows for local, regional, and international advocacy by all stakeholders, including parents. This article has shown what is needed, why it is needed and what is already working. The SIOP Global Mapping Programme is not just an academic exercise but is helping families across the continent identify where their child may receive treatment, resources for support during treatment and demonstrates the essential role played by NGOs in supporting these families. As a parent of a child who survived a childhood cancer, I confirm that the elements of childhood cancer care addressed here were essential to my daughter's recovery. All children/adolescents with cancer and their families deserve optimal care no matter their geography. ■

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Neil is co-founder of a group of parents (PORT) that reviews paediatric oncology clinical documentation for parents and patients.

He is co-chair of the SIOP Global Health Education and Training Working Group (POINTE) that helps LMIC clinicians find education or training to help them treat children with cancer. Neil is a founder member of the SIOP Global Mapping Programme.

Dr Joyce Balagadde Kambugu is a Consultant Paediatric Oncologist. She is the Director of Paediatrics at Uganda Cancer Institute (UCI), the National referral cancer treatment centre in Uganda. She is also the incoming Continental President of the International Society of Paediatric Oncology (SIOP Africa). With more than 10 years' experience in the field Joyce is a passionate advocate for childhood cancer in developing countries and believes that every child with cancer deserves the best treatment possible within the confines of available resources in their country. She is a member of the National Cancer Control Secretariat and is involved in development of the Paediatric National Control Plan

Lorna Renner is a consultant paediatrician with a specialization in paediatric oncology, Head of the Paediatric Oncology Service at the Korle Bu Teaching Hospital and Deputy Director of West African Genetic Medicine Centre. She is Chairperson for the Faculty of Child Health, Ghana College of Physicians and Surgeons. Dr Renner is also a past President of the African Continental Branch of the International Society for Paediatric Oncology (SIOP) and country project lead for World Child Cancer, a UK based charity, in Ghana. She is the recipient of several awards, most recently ASCO Women Who Conquer Cancer International Mentorship Award 2021.

Professor Kathy Pritchard-Jones is Professor of Paediatric Oncology, University College London Great Ormond Street Institute of Child Health, London, UK. She leads clinical and translational research in childhood kidney cancer and is a clinical lead within Health Data Research UK's digital innovation hub for cancer, DATA-CAN. She is President of the International Society of Paediatric Oncology (SIOP) at a critical time to support the global implementation of the WHO's challenge to double childhood cancer survival rates in low- and middle-income countries from ~30% to 60% by 2030. She was medical director for an integrated cancer system of healthcare providers serving a multi-ethnic population of 3.5 million in North London and continues to evaluate improvements to whole pathways of care.

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Korede Akindele is a seasoned professional with an uncommon blend of a strategic approach that implements actions to improve individuals, organizations and nations.

He is a childhood cancer advocate and Head of Programs at The Dorcas Cancer Foundation Nigeria, he currently serves in various global developmental roles.

Korede has impacted thousands of people, healthcare professionals, leaders and individuals in Africa and Middle East, improving understanding of the importance of early detection and proper treatment of childhood cancer.

He is actively involved in childhood cancer advocacy, awareness programmes, research, and events with the message of hope and survival for childhood cancer.

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Julia Challinor, RN, PhD, MS Education and MS Med Anthropology participates in multiple international projects in Africa, Asia and Latin America for childhood cancer and paediatric oncology nursing. As the International Society of Paediatric Oncology (SIOP) Secretary General, Dr Challinor chairs the Governance and Membership Committees and collaborates on actions related to SIOP's new strategic plan including work with the WHO Global Initiative for Childhood Cancer. She is a long-time member of the US Association of Paediatric Hematology/Oncology

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Since 2014, she has been involved in the creation and supervision of a Certified Diploma of Pediatric Oncology for clinicians in Francophone Africa. This is at the Mohammed V University of Rabat, and is recognized by the Paris-Sud University, France. Through this programme, she has developed the e-learning platform for paediatric oncology in Francophone Africa (www.e-gfaop.org).

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