



The My Child Matters programme: effect of public-private partnerships on paediatric cancer care in low-income and middle-income countries

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In low-income and middle-income countries, an excess in treatment failure for children with cancer usually results from misdiagnosis, inadequate access to treatment, death from toxicity, treatment abandonment, and relapse. The My Child Matters programme of the Sanofi Espoir Foundation has funded 55 paediatric cancer projects in low-income and middle-income countries over 10 years. We assessed the impact of the projects in these regions by using baseline assessments that were done in 2006. Based on these data, estimated 5-year survival in 2016 increased by a median of 5·1%, ranging from –1·5% in Venezuela to 17·5% in Ukraine. Of the 26 861 children per year who develop cancer in the ten index countries with My Child Matters projects that were evaluated in 2006, an estimated additional 1343 children can now expect an increase in survival outcome. For example, in Paraguay, a network of paediatric oncology satellite clinics was established and scaled up to a national level and has managed 884 patients since initiation in 2006. Additionally, the African Retinoblastoma Network was scaled up from a demonstration project in Mali to a network of retinoblastoma referral centres in five sub-Saharan African countries, and the African School of Paediatric Oncology has trained 42 physicians and 100 nurses from 16 countries. The My Child Matters programme has catalysed improvements in cancer care and has complemented the efforts of government, civil society, and the private sector to sustain and scale improvements in health care to a national level. Key elements of successful interventions include strong and sustained local leadership, community engagement, international engagement, and capacity building and support from government.

Introduction

Survival outcomes for the estimated 215 000 children younger than 15 years who are diagnosed with cancer every year vary strikingly across the globe.^{1,2} Steps to help improve outcomes for children with cancer are summarised in table 1, but, in low-income and middle-income countries, there are barriers at each step. In some countries, children might die before their family members or health-care providers suspect a cancer diagnosis; other patients might be referred with a suspicion of cancer but incorrectly diagnosed; others might succumb to their illness during the diagnostic process; and others might develop advanced incurable disease while awaiting diagnosis.^{1,3–6} Once a correct diagnosis is made, access to treatment can be hampered by financial constraints, distance between the patient's home and the oncology centre, availability of medications and other necessary treatments (eg, subspecialised surgery and radiotherapy), and a suitably adapted treatment regimen that can be safely delivered by centres across the country.^{7–18} Furthermore, a correct diagnosis and access to treatment are only the first steps to help improve outcomes because therapy abandonment, death from toxicity, and relapse are all common issues that patients with cancer must face in low-income and middle-income countries.^{2,8–10,12,19–25} Fortunately, there are proven interventions to help overcome each barrier in treatment failure for childhood cancer (figure 1), but these interventions require additional research to be deployed in new settings and scaled up to reach more patients.

In 2006, the My Child Matters programme was launched by the Sanofi Espoir Foundation to improve the outcomes of children with cancer in low-income and middle-income countries.^{26–29} The programme supports diverse projects in many of these countries and is designed to address various causes of treatment failure. In 2008, published results from a baseline assessment of paediatric cancer care in ten countries that had My Child Matters projects showed that postulated survival correlated most strongly (and significantly) with annual government health-care expenditure per capita.²⁸ However, government funding is not the only source of support for childhood cancer treatment, and the potential effect of non-governmental organisations (NGOs) on outcomes at the national level has not been documented. In this Policy Review, we assess the effect of the My Child Matters projects in the same ten countries and highlight the successes and challenges of the programme, after a decade of effort, which has supported 55 projects in 42 countries (figure 2).

The Sanofi Espoir Foundation funds the My Child Matters programme, which is led by the Medical Director of Sanofi Espoir Anne Gagnepain-Lacheteau and has a global call for projects every 3 years. Grantees are selected by an international scientific committee made up of paediatric oncology and global health experts and are selected according to the following five criteria: the potential to improve outcomes and reduce inequalities in childhood cancer care; the importance and expected effect of the issue addressed; the potential

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	Potential barriers	Sample indicators	Method of documentation	Selected My Child Matters projects
Correct diagnosis				
Recognition of possible cancer	Cancer not suspected by the family, family choose to consult alternative therapists or faith healers	Time from first symptom to consulting a health-care provider	Primary care registries	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Colombia, Guatemala, Egypt, Honduras, Morocco, Pakistan, Paraguay, Philippines, and Thailand
Arrival to primary care	Insufficient access to primary care, cancer not suspected by primary care staff	Time from first symptom to consulting a health-care provider, information given to family, laboratory work ordered, treatment offered	Primary care registries	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Colombia, Guatemala, Egypt, Honduras, Morocco, Pakistan, Paraguay, Philippines, and Thailand
Clinical diagnosis of cancer	Inadequate training of primary care providers to recognise signs and symptoms of cancer, no referral because of fatalism, use of complementary or alternative therapies	Number of primary care visits before referral to tertiary care, number of health-care providers consulted before appropriate referral, training and resources offered to primary care providers	Primary care and hospital-based cancer registries, medical records	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Colombia, Guatemala, Egypt, Honduras, Morocco, Pakistan, Paraguay, Philippines, and Thailand
Arrival to tertiary care	Distance, travel time, and other logistical barriers; absence of suitable paediatric cancer unit; no effective access because of inability to pay for services	Time from referral to arrival at a tertiary care centre for cancer	Hospital-based cancer registries, and medical records	African School of Paediatric Oncology, and projects in Colombia, Guatemala, Morocco, Paraguay, and Philippines
Histological diagnosis of cancer	Insufficient access to biopsy or to histochemical stains that are necessary for correct diagnosis, inadequate professional expertise	Time from arrival to tertiary care to diagnosis of cancer	Hospital-based cancer registries, and patient medical records	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Honduras, Morocco, Paraguay, Philippines, Senegal, and Ukraine
Access to treatment				
Access to staging and risk stratification	Inadequate access to radiology, histology, and biomarkers that are necessary to stratify the risk of patients	Method of staging and risk group assignment (clinical, radiographic, biomarkers), cancer-specific indicators	Hospital-based clinical registries	African Retinoblastoma Network, African School of Paediatric Oncology, Honduras satellite clinic project, and projects in Morocco, Pakistan, Paraguay, Senegal, Ukraine, and Venezuela
Assignment of correct treatment regimen	Assignment to a suboptimal regimen or one that is not adapted to local conditions	Comparison of treatment regimen to standard regimens used internationally	Hospital-based clinical registries	African Retinoblastoma Network, African School of Paediatric Oncology, African Research Network, African Retinoblastoma Network, and projects in Honduras, Morocco, Pakistan, Paraguay, and Thailand
Access to necessary chemotherapy and supportive care medicines	Temporary shortages or permanently unavailable essential medicines; inadequate access for the individual patient, even when the therapy is available in country	Number of times that access to a drug was delayed or a drug was unavailable during each treatment cycle; percentage of doses taken by the patient; percentage of doses taken by the patient on time	Hospital-based clinical registries	African Retinoblastoma Network, African School of Paediatric Oncology, African palliative care project, and projects in Guatemala, Morocco, Nicaragua, Pakistan, Paraguay, Philippines, Thailand, and Venezuela
Access to local control	Inadequate access to cancer surgeons or radiotherapy	Cancer-specific indicators for local control (eg, resection margins for patients with osteosarcoma who required amputation)	Hospital-based clinical registries	African School of Paediatric Oncology and projects in Morocco and Paraguay
Event-free survival				
Agreement to initiate therapy	Refusal of treatment due to financial, logistical, cultural, religious, or other obstacles or beliefs	Percentage of diagnosed patients who start therapy	Hospital-based clinical registries, NGO databases	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Honduras, Morocco, Paraguay, Philippines, Senegal, Tanzania, Thailand, and Venezuela
Completion of all necessary therapy	Abandonment of treatment due to financial, logistical, cultural, or other obstacles or uncontrolled symptoms during therapy	Cumulative incidence of abandonment of therapy among patients who started treatment	Hospital-based clinical registries, NGO databases	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Bangladesh, Guatemala, Honduras, Morocco, Paraguay, Philippines, Senegal, Tanzania, Thailand, and Venezuela
Supportive care	Treatment-related mortality (toxic death)	Percentage of early death (within 2 weeks of diagnosis), cumulative incidence of treatment-related mortality	Hospital-based clinical registries	African School of Paediatric Oncology, and projects in Honduras, Morocco, Nicaragua, Pakistan, Paraguay, Senegal, and Tanzania
Prevention of relapse	Inadequate adherence, medication shortages, and barriers to adherence	Percentage of available doses of medication taken and percentage of appointments missed by the patient	Hospital-based clinical registries, administrative databases, NGO databases	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Honduras, Morocco, Paraguay, Philippines, Senegal, Tanzania, Thailand, and Venezuela
Survival without disability				
After completion of treatment	Insufficient rehabilitation services, prosthetics, and adapted or high-technology therapies that minimise permanent morbidity from front-line therapy	Cancer-specific indicators (eg, for retinoblastoma, the percentage of patients with useful vision), late mortality	Health-related quality of life, disease-adjusted life-years saved	African Retinoblastoma Network, African School of Paediatric Oncology, and projects in Mali and Morocco

The potential barriers to a cure, and the projects that address them, are separated according to the phase of cancer care that the barrier affects. NGO=non-governmental organisation.

Table 1: Potential barriers and sample indicators to improve cancer survival outcomes in low-income and middle-income countries

for successful adaptation to serve as a reproducible model; methodological clarity and feasibility; and long-term sustainability and scalability. The My Child Matters projects are supported by regional and international mentors with expertise that is relevant to the proposal domains, and recipients gain access to the community of My Child Matters grantees to share best practices and develop local and international alliances.

Data collection

Monitoring and assessment

Oversight of My Child Matters projects includes mandatory periodic monitoring, financial audits, and site visits. Monitoring and assessment is done as part of a scientific advisory and management agreement with St Jude Children's Research Hospital. Projects are assessed according to project-specific indicators, which include infrastructure created, personnel trained, patients provided with palliative care services, treatment abandonment rates, and other indicators.

Data collection

Between June, 2016, and April, 2017, we assessed the implementation, effect, and sustainability of the My Child Matters projects by use of field surveys, interviews of key personnel, reports from project sites, site audits, hospital-based registries, and public data sources. We prioritised information gathered from public data sources, peer-reviewed publications, and hospital-based registries with direct access to anonymised, de-identified raw data (eg, registries in Honduras). We also used project reports provided to My Child Matters personnel as part of routine procedures, confirmatory site audits, summary data from hospital-based registries, field surveys, and interviews. Key indicators for assessment differed by project type (table 1, appendix).

Data analysis and survival estimates

We obtained cancer incidence data from population-based registries where they existed or from hospital-based registries and other sources.³⁰ For example, in Honduras, there are two paediatric oncology centres that receive all children with cancer in the country who are formally diagnosed and treated. All patients at each centre are registered in real time in a hospital-based registry from which cancer incidence was calculated.³¹ We compared derived incidence rates with the global estimate of annual childhood cancer incidence rates for 2001–10 of 140 cases per million children younger than 15 years, age-adjusted to the world age standard.³² The proportion of patients who had access to a correct diagnosis was calculated as the country-specific cancer incidence divided by 140 (table 2). Estimates of the rates of each cause of treatment failure were based on published results, population-based registries, hospital-based registries, disease-specific databases, and surveys. Rates of treatment abandonment and

misdiagnosis in high-income countries were extrapolated from published studies in subsets of countries or diseases.^{37,38} Proportions of patients with cancer who did not receive a diagnosis were taken from national incidence figures divided by the expected number of cases, which were based on the age-standardised world rates reported by the International Agency for Cancer Research.³² Proportions of people with no diagnosis are difficult to estimate in both high-income and low-income and middle-income countries and can differ by country, cancer type, and other factors. The two most commonly undiagnosed cancers are leukaemias, which can lead to death with a febrile illness that could be mistakenly attributed to infection, and brain cancer, which can lead to death from herniation with a misdiagnosis of a non-malignant neurological condition.³⁹ Although we estimated the rates of no diagnosis to be from 0% to 2% of children with cancer in most high-income countries, we used 1% for the purposes of this study.^{39,40} Misdiagnosis was defined as an incorrect diagnosis for which inappropriate therapy was provided and did not include preliminary diagnoses that are altered before starting therapy or after minimal therapy that would not affect the prognosis. For example, a misdiagnosis of sarcoma and provision of several months of sarcoma therapy when the patient had lymphoma would be considered a misdiagnosis, whereas providing a week of prednisone to a patient with a provisional diagnosis of acute lymphoblastic leukaemia who was then diagnosed and treated for acute myeloid leukaemia would not be considered a misdiagnosis. On the basis of second opinions provided by colleagues in high-income countries and a pathology review of patients who had seemed to relapse, but were discovered to have had another diagnosis, the rate of misdiagnosis was estimated to be 2% in high-income countries. However, for some cancers, such as Wilms' tumour, the

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See Online for appendix

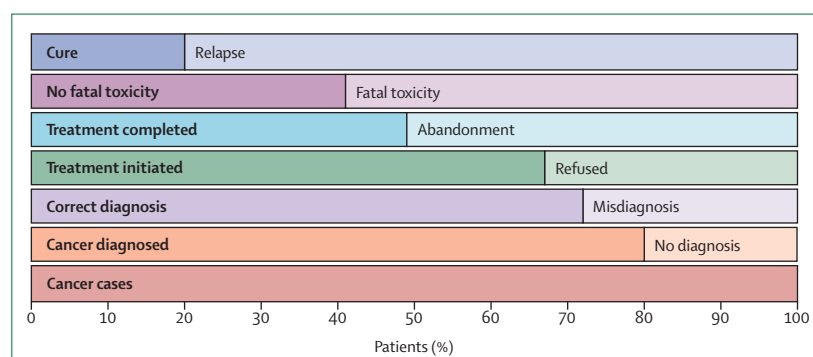


Figure 1: Steps to treatment success and interventions to address specific causes of treatment failure for children with cancer in low-income and middle-income countries

Interventions to address each cause of treatment failure include: relapse—access to medication, adherence promotion; toxic death—infection prevention and control, supportive care; abandonment and refusal of treatment—psychosocial, financial, and logistical support; access to care close to home; patient and family education; misdiagnosis—professional training, pathology programme, equipment, and reagents; no diagnosis—societal awareness, access to primary care, medical alertness, effective referral, access to tertiary care, logistical support.

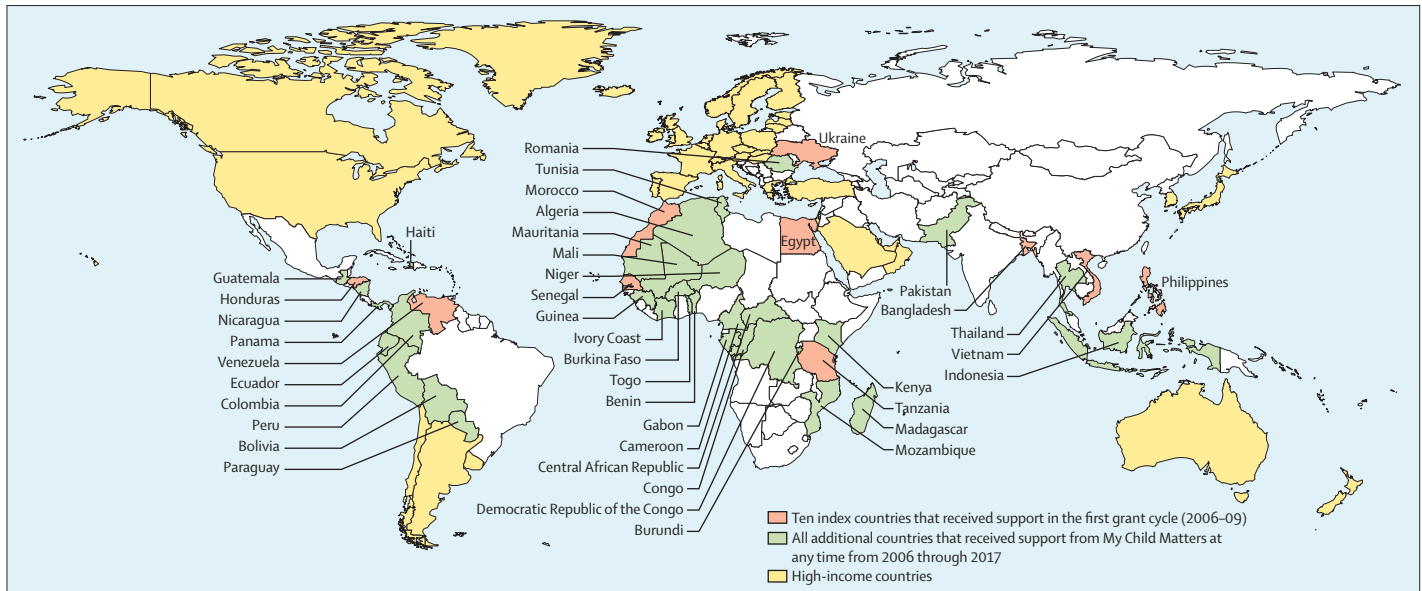


Figure 2: Countries with My Child Matters projects, including ten index countries

The My Child Matters Programme includes 55 projects in 42 countries. Of the ten index countries, Honduras, Paraguay, Senegal, Morocco, and the Philippines have projects that remain active in the 2017 grant cycle.

misdiagnosis rate might be as high as 3·5% in part because treatment in many countries is based on a radiological diagnosis, and surgical resection for definitive diagnosis occurs subsequently.⁴¹

We estimated survival as the product of correct cancer diagnosis, access to treatment, and 5-year event-free survival of patients treated, which was used as a surrogate for improved outcome. For example, a country where 50% of children with cancer are correctly diagnosed, 50% of patients who are diagnosed are treated, and 50% of treated children survive 5 years without relapse would have a national 5-year survival rate of 12·5%. Estimated survival was statistically compared with government health-care spending per capita by use of Pearson's correlation.⁴² Primary outcomes included the change in survival rates from the 2006 baseline to 2016 in ten index countries that benefited from the very first cycle of My Child Matters Grant Award, 2006–09. Four of the ten index countries (Honduras, Senegal, Morocco, and the Philippines) continue to receive support during the 2017 grant cycle; correlates of paediatric cancer survival in low-income and middle-income countries that factored in non-governmental organisational support; and identification of essential features associated with sustained programme effects. Most projects focused on specific improvements in limited geographical areas and would not be expected to affect survival at the national level, but were meant to serve as catalysts for further progress. A qualitative synthesis of effect, sustainability, and scalability was done and we identified key indicators that applied equally well at any geographical level and across cancer types. No systematic literature search was

done. Rather, the reference list was derived from several non-systematic searches and a compilation of the authors' own files.

Findings

Project effect

Outcomes of the My Child Matters projects in the ten index countries, for which 10 years of project follow-up were available, are summarised in the appendix. The strong correlation between government health-care spending per capita and childhood cancer survival postulated in 2006 (Pearson's $r=0\cdot882$, $p<0\cdot001$) was also evident in 2016 (Pearson's $r=0\cdot826$, $p=0\cdot003$). Survival estimates increased by a median of 5·1% (range from –1·5 to 17·5%), which corresponds to an overall improvement of an estimated additional 1343 children per year of the 26 861 children who developed cancer in 2016 in the ten index countries (table 2).

Correct diagnosis

In several projects, the proportion of correct diagnoses was improved by the promotion of timely diagnoses, which included awareness campaigns, town hall meetings, and education for primary health-care workers in Egypt, Honduras, Morocco, the Philippines, and Vietnam. Improved knowledge, earlier referral, and fewer extraocular retinoblastomas (a marker of late diagnosis) were documented (appendix). Improvements to pathology services and flow cytometry were part of the projects in Morocco, the Philippines, Senegal, and Ukraine, where laboratory personnel were trained in the latest methods of leukaemia diagnosis.

	Bangladesh	Egypt	Honduras	Morocco	Philippines	Senegal	Tanzania	Ukraine	Venezuela	Vietnam	Totals, weighted averages
Total population ¹ in 2016 (in thousands)	162 911	93 384	8190	34 817	102 250	15 589	55 155	44 624	31 519	94 444	642 884
Population of children younger than 15 years in 2016 (in thousands) ²³	47 132	31 283	2541	9460	32 412	6824	24 900	6756	8765	21 795	191 867
Under-5 mortality (per 1000 livebirths) in 2015 ²⁴	37.6	24.0	20.4	27.6	28.0	47.2	48.7	9.0	14.9	21.7	42.5
Per capita GDP (US\$) in 2016 ²⁵	3891	12 554	5271	8330	7728	2557	3080	8305	13 761	6429	..
Total per capita health-care expenditure (US\$) in 2014 ²⁶	31	178	212	190	135	50	52	203	873	142	..
Per capita public health-care expenditure (US\$) ²⁶	9	68	108	64	46	26	24	103	256	77	..
Health-care expenditure from public funding sources (%)	29	38	51	34	34	52	46	51	29	54	..
Per capita GDP used for health care (%)	3	6	9	6	5	5	6	7	5	7	..
Crude incidence rate of cancer in children younger than 15 years, per million [*]	86.2	119.1	90.0	127.8	135.3	55.2	55.2	136.8	129.8	116.7	98.6
New childhood cancer cases expected in 2016†	6598	4380	356	1324	4538	955	3486	946	1227	3051	26 861
Estimated new childhood cancer cases diagnosed in 2016†	4062	3381	317	1022	3784	376	1373	924	1138	2544	18 924
Estimated correct diagnosis in 2016 (%)	59	72	93	72	74	39	93	96	93	79	74
Access to treatment in 2016 (%)‡§	50	100	100	100	80	100	50	100	90	100	77
Event-free survival in 2016 (%)§	25	60	49	50	25	39	30	70	70	26	37
Postulated cure rate in 2016 (%)§	7	43	46	36	15	15	14	68	59	21	23
Postulated cure rate in 2006 (%)§	5	40	40	30	10	5	10	50	60	5	18
Change in 5-year survival from 2006 to 2016 (%)	+2.3	+3.3	+5.5	+6.1	+4.7	+10.4	+3.9	+17.5	-1.5	+15.5	+5.5
Estimated additional survivors per year (2016 vs 2006)¶	132	131	21	79	227	96	139	170	-12	488	1343

*Crude rates for relevant world regions in 2001–10 reported by Steliarova-Foucher and colleagues²⁷ were applied for Bangladesh, Senegal, Tanzania, and Venezuela. Crude rates reported by Steliarova-Foucher and colleagues²⁸ were applied for Egypt (Gharbia; 1999–2010), Honduras (Francisco Morazán; 2002–12), Morocco (Casablanca and Rabat; 2005–12), Philippines (Manila and Rizal; 1993–2012), Ukraine (2002–12), and Vietnam (Ho Chi Minh City; 1995–2013). †Estimated by assuming an incidence of 140 cases per million children (younger than 15 years) per year, on the basis of the most recent available international age-adjusted registry information.²⁹ ‡Access to treatment is defined as the percentage of patients who can afford treatment or for whom treatment is provided by a public health system or insurance programme. This percentage is not related to the quality of the treatment offered, gaps in effective access to specific therapies or medications, or other factors that influence cancer outcomes. These factors affect the event-free survival because they lead to excess relapse, death due to treatment toxicity, and treatment abandonment rather than by a lower percentage of access to treatment. §Reported percentages were estimated from information collected in surveys and extrapolations from hospital-based registries and published results. ¶Calculated by applying the estimated increase in cure rates from 2006 to 2016 to the expected number of children who developed cancer in 2016.

Table 2: Population and macroeconomic information and comparison of survival between 2006 and 2016 in the ten index countries of My Child Matters

Access to treatment

A primary focus of the Tanzania project was to provide locally adapted care and subsidised transportation for children with Burkitt's lymphoma. Access to treatment for children who were diagnosed with Burkitt's lymphoma increased from 20% to 65%. The Senegal paediatric oncology ward was expanded and renovated to accommodate 18 inpatient beds in total and three new outpatient areas, which improved access to timely hospital admission and chemotherapy administration. Although My Child Matters projects do not fund medications, several of these projects had complementary parallel efforts to improve medication access, as was the case with the French African Pediatric Oncology Group who provided medications through research and philanthropic grants, the Philippines' PhilHealth public insurance plan, and Morocco and Tanzania through NGOs.

Event-free survival

Event-free survival depends on the prevention of therapy abandonment, reducing death due to treatment toxicity, and decreasing relapse. In Honduras, the development of satellite clinics and training for health-care professionals were associated with a 17% reduction in treatment abandonment, whereas psychosocial support for patients at the National Cancer Hospital in Hanoi, Vietnam was associated with a 32% decrease in treatment abandonment (appendix). Despite severe social and economic problems in Venezuela, the psychosocial support and family education programme was associated with a modest (but not significant) decrease in treatment abandonment, from 5% to 4%. Although no programme focused specifically on reducing death due to treatment toxicity, training programmes for nurses and doctors in Honduras, Morocco, the Philippines, Senegal, and Vietnam included components related to infection

prevention and control. Prevention of relapse depends on sustained access to treatment, the use of suitably adapted protocols, and logistical support for transportation and access to services—elements that were included in many of the My Child Matters projects.

Palliative care

In addition to modest gains in treatment outcomes, access to palliative care was increased in many of the index countries because of the My Child Matters projects. In Morocco and Senegal, for example, educational materials were developed and distributed at training workshops for health-care professionals. Continued access to palliative care information in French is provided by the French African Pediatric Oncology Group. In Bangladesh, 160 doctors and nurses were trained in palliative care provision, and palliative care inpatient bed capacity increased from nine to 53 during 2006–16. The ASHIC Foundation, Bangladesh's first NGO dedicated to childhood cancer, has provided support (including lodging and hospice care) to 410 families over the past 10 years, while the training, awareness, and advocacy programmes have catalysed a striking expansion in palliative care services for both children and adults in the Bangladeshi public health-care system.

Case studies on sustainability and scalability

The themes identified during the ongoing projects in the ten index countries led to the development of new projects to address identified issues in increased depth and of increased scale, three of which we chose as representative case studies to demonstrate the scalability and sustainability of the programme (table 3).

Paraguay Childhood Cancer Care Network

Children with cancer in Paraguay are treated in one of three health-care systems: the Ministry of Health hospitals, the National University of Asunción (which has a medical school), or social security system hospitals (available to workers whose employers have contributed to the social insurance system). Each system had distinct personnel, protocols for each cancer, and referral patterns, with no system of communication between different institutions within the same system or from the other two systems. In some cases, a centre of excellence—for example, in neuro-oncology—was available in one system but not in the others, such that patients' care depended on the hospital to which they were referred to and their eligibility for services there.^{11,17} Furthermore, inefficient and confusing referral patterns have led to delayed diagnoses and, in some cases, death before diagnosis. Finally, insufficient numbers of trained paediatric oncology personnel, heterogeneous diagnostic capabilities, and high rates of treatment abandonment have led to poor outcomes, even after the arrival of the patients to tertiary care.

The goal of the My Child Matters project in Paraguay was to establish the Red Nacional de Atención del Cáncer

Infantil (National Childhood Cancer Care Network; RENACI), decentralise outpatient oncology care, facilitate early diagnosis, promote effective referral, standardise treatment protocols, and provide outpatient care to patients with a diagnosis and treatment plan given at the tertiary care centre. Started in 2009 by the Paediatric Cancer Centre of Asunción and the Asunción School of Medicine, RENACI allowed patients to receive some components of therapy close to home to reduce travel burden, time away from work, and logistical obstacles related to child care for healthy siblings, which improved quality of life for the entire family.⁴³

The programme trained 4094 health-care professionals at the National University School of Medicine and at the regional satellite clinics to promote early diagnosis and appropriate referral.⁴³ Communication was improved by implementing an electronic patient registration and follow-up system, which allowed timely rescheduling of missed appointments, tracking of patients locally, and paves the way for future integration with the national cancer registry. The results of the programme are summarised in table 3. Two outcomes deserve special mention: the programme uptake was surprisingly quick, with an increase from 81 patients seen at a satellite clinic in 2009 to 884 in 2015; and the rate of treatment abandonment for children with acute lymphoblastic leukaemia in Paraguay decreased from 17.5% of children with cancer diagnosed in 2009, to 0% of those diagnosed in 2015.^{27,43} These two improvements were attributed to the fact that clinicians at the satellite clinics reinforced key educational messages about adherence to therapy and expeditiously managed treatment side-effects close to patients' homes. Finally, as of 2015, the procurement of medical equipment and supplies has allowed 61 patients to get locally prepared chemotherapy treatment at the satellite clinics, and, as local providers gain experience, provision of low-risk outpatient chemotherapy by the satellite clinics will hopefully become the norm.

Because the satellite clinics of the RENACI network are available to patients treated in any of the three health-care systems of Paraguay, the programme has served to connect the various public health institutions in the country and catalyse the harmonisation of oncology care regardless of whether it is provided by the Ministry of Health, the National University of Asunción, or the social security system. Hopefully, this increased communication between the three health-care systems will pave the way for a more coordinated approach to care for all Paraguayans, in addition to children with cancer.

Mali Retinoblastoma Programme

In high-income countries, more than 95% of children with retinoblastoma have disease limited to the eye (intra-ocular), and preservation of useful vision is possible in most children even when they have bilateral tumours.⁴⁴ However, in low-income and middle-income countries, many patients present with extraocular

For more on the French African Pediatric Oncology Group see <http://www.gfaop.org/formation.php>

Project focus areas		Project description	Indicators of effect	Project results	Project-related and external factors that affect sustainability and scalability (leadership, community engagement, international engagement, capacity building, and government)
African School of Paediatric Oncology (2006–present)	Human resource development and capacity building; pain management and palliative care; research network development	To initiate a university-accredited 1-year clinical paediatric oncology diploma programme for paediatricians practising in French-speaking African countries; to increase knowledge and clinical expertise in the management of children with cancer in their local contexts; to provide intensive training courses for nurses, nurse educators, pathologists, radiation therapists, and paediatric surgeons	Number of physicians who completed the certificate programme; graduation rate of those who started the programme; retention rate of trainees in home country after training abroad; number of physicians currently in training; number of new paediatric oncology units established by graduates; nurses who have been trained through the programme (including components in Morocco and in France)	42 physicians (of 51 who started the programme) from 16 countries completed the programme; 82% graduation rate, with 100% retention rate; 21 physicians in training; two new units created; 100 nurses trained	Leadership—continuous leadership by Moroccan and French professors has been sustained for the past decade at multiple levels of the programme, including medicine, nursing, surgery, and pathology; community engagement—awareness campaigns in participating countries have led to more patients being diagnosed and to the creation of new paediatric oncology units in Niger and the Central African Republic; GFAOP protocols, data management programmes, and palliative care training programmes all work synergistically with the African School of Paediatric Oncology to improve care; international engagement—in addition to Sanofi Espoir, GFAOP is supported by NGOs in France and Morocco; a palliative care training programme has been added and has leveraged the success of the school; development of a research network has also been done within GFAOP to support monitoring, evaluation, and ongoing programme improvement; capacity building—all trainees had documented improved knowledge and capability to manage paediatric patients with cancer, based on exams after each module and hands-on patient care experiences with observation by clinical mentors; two new paediatric oncology units have been established in regions where none existed; a distance-learning (electronic-learning) platform has provided access to all content plus periodic updates so that trainees can review information previously mastered and have access to updates and new materials; government—the governments of Morocco and France have participated directly, through the support of public universities (Rabat and Paris XI) where the educational programmes are provided
	Promoting early diagnosis of retinoblastoma and improving access to care; improving event-free survival by developing a collaborative network of African centres of excellence	To raise awareness about retinoblastoma and childhood cancers by use of public campaigns to promote early diagnosis; to train oncologists and ophthalmologists to manage retinoblastoma; to create infrastructure and expertise for vision conservation in children diagnosed at early stages; to provide ocular prostheses, rehabilitation, and psychosocial support to patients with advanced disease	Patients diagnosed from 2011 to 2016; patients with extraocular disease at presentation; 1-year survival for patients with unilateral or bilateral intraocular disease; eye preservation rates for patients with intraocular disease in 2015 and 2016 (compared with none before 2015)	201 patients diagnosed; decrease in patients presenting with extraocular disease from 17 (65%) of 26 in 2011 to 19 (42%) of 45 in 2016; 1-year survival for patients with unilateral intraocular disease increased from 3 (43%) of 7 in 2011 to 10 (71%) of 14 in 2016; 1-year survival for patients with bilateral intraocular disease increased from 0 (0%) of 2 in 2011 to 5 (42%) of 12 in 2016; eye preservation for patients increased from 0 (0%) of 4 in 2011 to 5 (21%) of 24 in 2016	Leadership—local and international leadership has been provided by several key individuals since programme inception in 2011; community engagement—World Alliance Against Cancer, the multinational French-speaking African branch of the International Network for Cancer Treatment and Research, supports the African Retinoblastoma Network and is working to expand it to additional countries; international engagement—in addition to ongoing financial and technical support from My Child Matters and the Curie Institute (referral centre for retinoblastoma in France), clinicians have regional support within the GFAOP; capacity building—all children with retinoblastoma in Mali are tracked in a central registry; the system for diagnosis and referral remains in place and the multidisciplinary care team remains clinically active. Since 2012, patients who undergo enucleation have had access to an ocular prosthesis; government—the retinoblastoma programme was developed in two public hospitals in Bamako
Paraguay Childhood Cancer Care Network (2009–present)	Treatment adherence and completion; health-care system development	To reduce treatment abandonment through improved access to care; to create a network of satellite clinics across the country, affiliated with the Asunción University's School of Medicine, with the aim of providing good quality cancer care closer to patients' homes	Infrastructure created; number of patients seen at satellite clinics; treatment abandonment rate for acute lymphoblastic leukaemia	A network of four satellite clinics was established in eastern, middle, northern, and southern regions of Paraguay (RENAACI Network); and Electronic Patient Registration and follow-up system was established; number of patients seen increased from 81 (in 2009) to 884 in 2015; percentage of patients with acute lymphoblastic leukaemia decreased from 17.5% before 2009, to 0% after 2011	Leadership—local leaders who started the programme have remained continuously involved for the past decade; community engagement—the RENACI network and foundation started by My Child Matters has continued to function; efforts are ongoing to strengthen and integrate the three health-care systems through sharing of knowledge, expertise, resources, and treatment regimens; international engagement—physicians and government officials have continued to work with partners in the USA and Europe to further improve outcomes and build additional research and training capacity; capacity building—improved infrastructure and expertise at each clinic to deliver high-quality paediatric cancer care; creation of the Paediatric Society for Haematology and Oncology has provided a forum for national exchange among professionals from all three health-care systems; government—adoption by the Paraguayan Parliament of the FONARES Law, by which the Ministry of Health endorses specific national protocols and guarantees financial support for paediatric cancer through subsidised drug procurement; tripartite collaboration has been formalised by a signed memorandum of understanding between the Ministry of Health, the Social Security System, and the National University of Asunción

GFAOP=French African Paediatric Oncology Group. NGO=non-governmental organisation.

Table 3: Case studies of three My Child Matters projects that exemplify sustainability and scalability

disease and have cure rates that are close to 0%.⁴⁵ Indeed, in 2011, 65% of patients presented with extraocular disease, of which none of them survived. Even those with unilateral intraocular disease at diagnosis had a survival of only 43%, compared with 95% in high-income countries (table 3).

The World Alliance Against Cancer partnered with GFAOP and the Curie Institute to develop retinoblastoma treatment centres in several French-speaking African

countries, starting with Mali in November, 2011.⁴⁶ The aims of the project included the early diagnosis of retinoblastoma; rapid access to ophthalmic diagnostics and surgery, followed by rehabilitation with ocular implants made on site; access to conservative treatment for localised tumours with thermochemotherapy (since August, 2014); case registration and outcome assessment; communication and collaboration between project sites; expansion to other sub-Saharan African

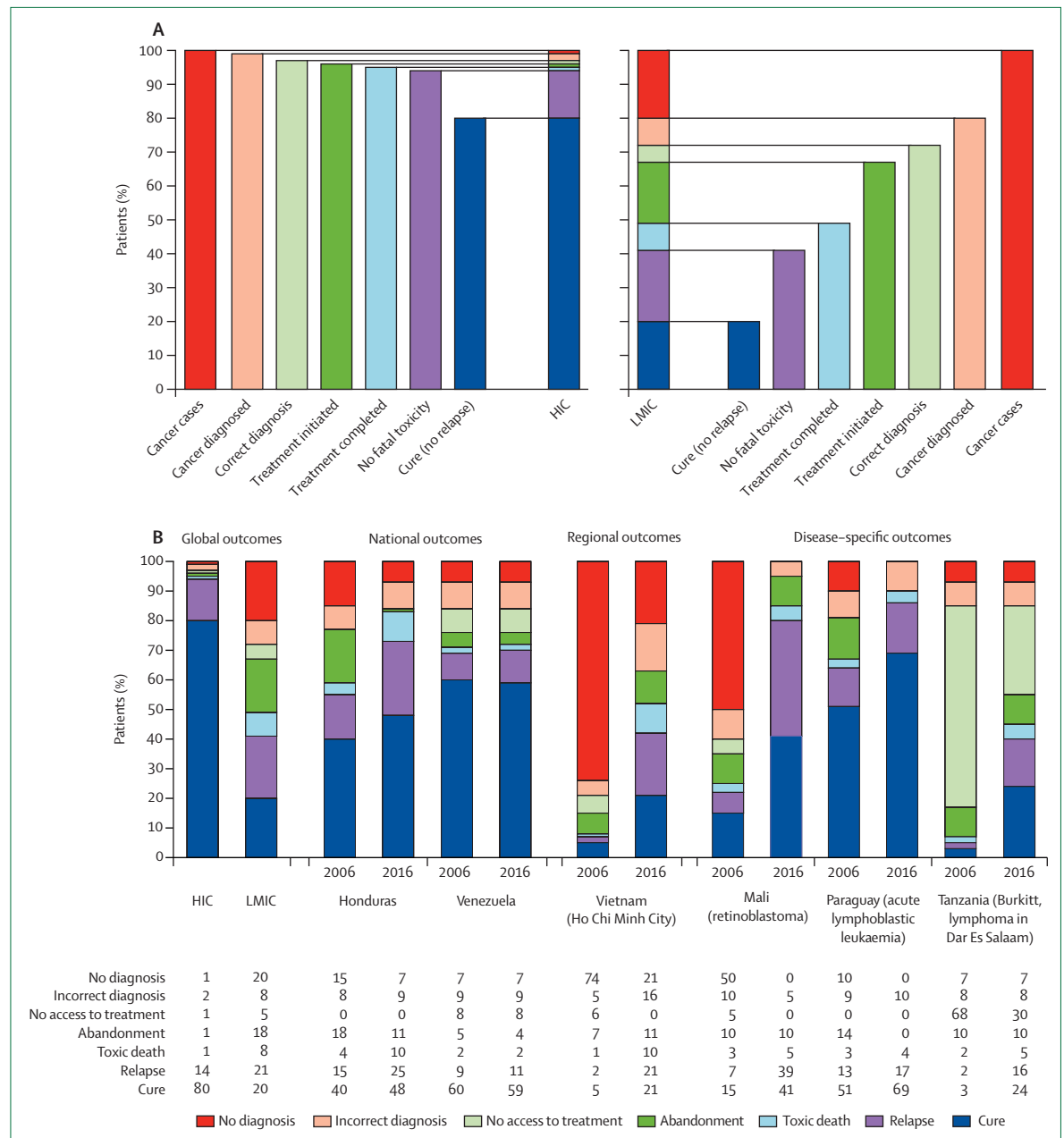


Figure 3: Distribution of causes of treatment failure and outcomes for children with cancer

(A) Causes of treatment failure for children with cancer in high-income countries versus low-income and middle-income countries. (B) Distribution of global, national, regional and disease-specific outcomes for children with cancer in selected countries with My Child Matters Projects. HIC=high-income countries. LMIC=low-income and middle-income countries. Reproduced by permission of Howard SC.

countries; and appropriation or continuation of the programme by local authorities.

The funded project started in Mali, where it has had a substantial effect on cancer care in the country (figure 3, table 3).⁴⁶ The project has been extended to the Democratic Republic of the Congo, Senegal, Ivory Coast, and Madagascar. Hopefully, the project will not only extend to other countries, but also lead to greater depth and breadth of actions within each country, until results approximating those of high-income countries are achieved.⁴⁵

African School of Paediatric Oncology

Although trained personnel are necessary to implement interventions to help improve cancer survival outcomes, many French-speaking African countries have woefully inadequate numbers of physicians and nurses with paediatric oncology expertise. The African School of Paediatric Oncology was developed by GFAOP under the auspices of the My Child Matters programme to train physicians, nurses, and other professionals to deliver paediatric cancer care that is adapted to local contexts. Each of the school's components addressed a specific need in the cancer care continuum: the establishment of a multidisciplinary 1-year programme to train oncology physicians and oncology nurses that includes courses and practical clinical training of 25 physicians per year, at the Rabat School of Medicine of Mohammed V University, Morocco and endorsed by the Paris-Sud School of Medicine; a nurse development programme including an intensive course for nurse educators; support for trainees to implement new paediatric oncology pilot units in their countries of origin if none existed already; and an innovative electronic-learning (e-learning) programme initiative that includes all course materials, video recordings of lectures delivered during the course modules, a repository of articles, and other content that is now available before trainees arrive, during the course, and after they return home. The course content, practical clinical training experiences, and e-learning have all been developed specifically to enable a paediatrician or general physician to learn the fundamentals of oncology care and to practise in their local context. This approach addresses the many problems inherent to training abroad, including high costs (and therefore low access to training), long duration of training, a focus on many aspects of oncology that are not relevant after the trainee returns home, and the risk that the trainee will not return home after completing the programme. The 1-year certificate is practical, is provided at no cost to the trainee, and, through integration within GFAOP, includes long-term mentoring, networking, continuing education, and clinical research infrastructure support for the implementation of shared protocols after the trainee returns home.⁴⁷⁻⁴⁹

To date, 42 physicians from 16 different African countries have completed training, which represents 82% of those who enrolled, and 21 more were receiving training in 2017 (table 3). All physicians have returned

home to practise and have remained engaged with their professors (and with each other). In two cases, in Niger and the Central African Republic, new oncology units have been established. Similarly, intensive training sessions for nurses have provided them with an in-depth understanding of childhood cancer care, tools for psychosocial support of patients and their relatives, and educational strategies to return to their countries of origin and develop cohorts of locally trained nurses. Training in parallel with physicians and sharing lectures and training experiences also promotes the concept of a multidisciplinary team, which is further modelled by the professors and instructors in France and Morocco.⁵⁰ To date, more than 100 nurses have been trained, and the programme is fully integrated into the two sponsoring universities. Indeed, the emphasis on the important role of nursing in oncology has led to the development of additional formal training programmes for nurses in Morocco including advanced degrees in administration and pedagogy for nurses, and planning for development of advanced practice nurses whose scope of practice would include medical decision making, prescribing chemotherapy, and performing procedures like lumbar puncture, as is the case in many high-income countries.⁵¹

Discussion

Programme effect and sustainability

Most of the My Child Matters projects were implemented in localised areas and, therefore, they would not be expected to substantially affect survival at the population level. Additionally, many other efforts by individuals, academia, government, and other NGOs were undertaken in the same countries during the same study period (appendix). We did not attempt to distinguish the direct effects of the My Child Matters projects from the synergistic effects that they had with other efforts and from catalytic effects that led to new and expanded efforts by government and other stakeholders. Indeed, one sustainability factor that probably affects projects in all countries is the increased attention to non-communicable diseases in low-income and middle-income countries at all levels of society and by global organisations, such as WHO.

Limitations of estimates

The assumption that the annual incidence of childhood cancer is 140 per 1 million children younger than 15 years in low-income and middle-income countries is based on the observation that incidence rates and distributions of different cancer types are uniform in countries where population-based registries exist. Indeed, even in low-income and middle-income countries, the incidence of solid tumours varies little from country to country, except in HIV-endemic areas, where Kaposi's sarcoma and other AIDS-associated cancers are most common.^{2,52} However, the reported incidence of leukaemias and brain cancers is much lower in low-income and middle-income countries than in high-income countries, presumably because

patients die before a diagnosis of cancer is made and because the cause of death is attributed to other factors, such as malaria, infection, or seizure.⁵² The calculation of the percentage of children with cancer with a correct diagnosis is predicated on the assumption that patients who received a diagnosis and were registered in a database had a correct diagnosis. Therefore, this calculation overestimates the rate of correct cancer diagnoses. Because rates of misdiagnosis are usually not well quantified, the magnitude of this overestimation is unknown. However, in a study⁵³ that assessed patients from low-income and middle-income countries who were referred for second opinion at a centre of excellence in the USA, the percentage of major disagreement in diagnosis, defined as differences that would affect treatment, ranged from 13·7% to 37·1% in countries that provided the most data. Poor availability of immunohistochemistry services and insufficient training of pathologists in the diagnosis of paediatric neoplasms were cited as contributors to the discrepancies in diagnosis.^{53,54} Because few children who have had an incorrect diagnosis become event-free survivors, the overestimation of the rate of correct diagnosis would not lead to an overestimation of the final survival rate, but would misclassify the cause of treatment failure as relapse without necessarily recognising that the relapse was caused by the selection of an inappropriate treatment regimen due to misdiagnosis. Estimates of treatment abandonment, death due to treatment toxicity, and relapse rates were confined to regions or countries where patient-level data were available (figure 3). The feasibility of registering every child with cancer in real time by use of integrated hospital-based and regional registries has been documented in Honduras, Venezuela, Paraguay, Colombia, and other countries, and should become the standard for all patients with chronic or life-threatening diseases for progress in health care to be accelerated. Finally, our overview provides a summary of the effect of the My Child Matters programme on a global level but cannot describe in detail the specific aspects of each funded project. The individual projects provide additional local and generalisable insights, and each one deserves a separate publication. Indeed, we anticipate that local team members who led each individual project will publish papers related to their projects in turn.

Contributors to project success, sustainability, and scalability

Several themes emerged from the assessment of the projects in the ten index countries, including the importance of local leadership, community engagement, international engagement, capacity building, and government (panel). A sustained local leadership, by a core group of key people who remained committed to the project for many years, strongly predicted successful outcomes. Projects that had sustained complementary support from local NGOs, such as the Lalla Salma Foundation (in Morocco) and the ASHIC Foundation

(in Bangladesh), were better able to scale up activities to address more causes of treatment failure, to treat larger numbers of patients, and to extend the programme to more regions of their country. These benefits were even more pronounced where the efforts of local NGOs were complemented by external NGOs, such as GFAOP and the World Alliance Against Cancer.

Local leadership

Cancer care is complex, with numerous steps needed to improve outcomes, and optimal interventions differ in each setting. Therefore, only strong and sustained leadership can result in lasting improvements in this area of health care. A dedicated local leader, with a stable position and salary, can implement existing programmes, such as those in the legend of figure 1, and develop and test new ones. Local leaders can effectively engage the community and harness the resources of local NGOs and international partners to help meet specific local needs. Local leaders can recruit, train, and empower other health-care professionals to build human capacity that has an effect far beyond what could be achieved by a single individual. Although it is difficult to quantify, we consider sustained and dedicated local leadership to be the most important predictor of long-term success, because the other four sustainability factors all depend on local leadership to harness and coordinate them.

Community engagement and NGOs

Engagement of community members and local NGOs was part of every project, and the appendix summarises the combined effects of the My Child Matters projects with NGOs, community and academic leaders, and other partners that were working toward common goals. For example, providing guest houses for patients who live far from the treatment centres was funded by local NGOs, or by local NGOs and governments and was a key component of the programmes to prevent treatment abandonment in Egypt, Honduras, Morocco, the Philippines, Tanzania, Venezuela, Vietnam, Paraguay, and several French-speaking African countries. Without this support and the existence of other parallel projects to reduce death from infection and facilitate correct diagnosis, the projects funded through My Child Matters would have had less impact. Indeed, engaged community members and NGOs might be the most powerful force for the sustainability of projects (figure 4), especially where government support for childhood cancer is intermittent or at risk of defunding because of economic hardships, as in Venezuela, where childhood cancer cure rates have been maintained despite the collapse of the national economy (figure 3B).

International engagement and collaboration

International collaborators from academic institutions in Africa, Europe, and North America contributed greatly to My Child Matters programmes and provided mentorship, funding for complementary projects, and support for

Panel: Contributors to project success, sustainability, and scalability**Local leadership**

- A dedicated local leader with a stable position and salary can implement, sustain, and scale existing successful programmes and develop and test new ones
- Local leaders can effectively engage the community and harness local non-governmental organisations (NGOs) and international partners to help meet specific local needs
- Local leaders can recruit, train, and empower other health-care professionals to build human capacity that has an effect beyond that of a single individual

Community engagement and NGOs

- Engagement of community members and local NGOs was part of every successful project
- Local community members and NGOs provide support groups, logistical support, housing, and other services that prevent treatment abandonment and reduce the probability of death due to treatment toxicity
- Engaged community members and NGOs might be the most powerful force for sustainability, especially when government support for childhood cancer is intermittent, or at risk of defunding because of economic hardships

International engagement and collaboration

- International collaborators from academic institutions on several continents provided mentorship, funding for complementary projects, and support for teaching and research activities
- International collaborators can support and legitimise the work of local leaders and provide external validation when necessary
- Regional networks provide a framework for multi-country collaboration, shared protocols and best practices, and multicentre project development
- Connected health-care professionals and community members from five continents can encourage each other and share best practices and innovations

Capacity building

- Human capacity is the foundation on which all progress in health care rests and, therefore, training and mentoring programmes were an essential part of all projects
- Training and providing stable positions for multidisciplinary oncology health-care providers allows physicians, nurses, pharmacists, and others to develop expertise
- Systematic orientation of new professionals, especially nurses, and assuring that they have stable positions in the

oncology service (rather than short period rotations) ensures that a core of experienced people remains available to care for patients and mentor the next generation of providers

- Infrastructure, including oncology units and stable funding for key personnel, allows trained professionals to focus on patient care, quality improvement, and locally relevant research in the public health-care system, rather than having to seek second and third jobs in the private sector to earn a living

Government

- Government support provided an important impetus towards sustainability in several projects
- Standardisation and inclusion of cancer awareness and education campaigns in the public health-care systems has increased the probability of long-term sustainability and impact
- Governments can increase access to essential chemotherapy via public health insurance and by facilitating regulatory approval and logistical support to import and deliver essential generic medications
- Governments can encourage and promote the activities of local oncology leaders, NGOs, health-care providers, and international collaborators to increase their effect and remove barriers to progress

Enabling technologies—education, communication, and data management

- Education with online lectures, email consultation, web-based discussion groups, and regional meetings with support from experts participating virtually is now feasible almost everywhere
- International organisations, such as the International Society of Paediatric Oncology, and specific institutions, such as the St Jude Children's Research Hospital's Cure4Kids website, deliver free educational content to their constituents and users around the globe and provide a platform for online discussion at no cost to users
- Paediatric oncology databases available at no cost to users in low-income and middle-income countries include Redcap, the Resonance Patient Center, and others; preconfigured tools for patient care, quality improvement, and locally relevant research allow clinicians to focus on their work rather than on the creation of infrastructure, and a global community of users on the same platform facilitates data interoperability, collaboration, and rapid diffusion of both standards and innovations

teaching and research activities. Regional networks, such as GFAOP, provide a framework for multicountry collaboration, shared protocols and best practices, and multicentre project development, such as the Mali Retinoblastoma Programme, the African School of Paediatric Oncology, and the palliative care network and research network. For example, the My Child Matters project in Senegal funded the renovation of a dedicated

oncology ward and the training of key staff, some of whom attended the African School of Paediatric Oncology and all of whom used GFAOP treatment protocols. Independent local leaders, supported by local NGOs and international networks of like-minded colleagues, have sped up and sustained the progress made. A notable benefit of My Child Matters is its role as a catalyst for long-term, multinational, and multidisciplinary



Figure 4: Public awareness and signature campaign for childhood cancer in the Philippines
This Relay for Life event was one of a series of public awareness and advocacy campaigns for childhood cancer as part of the My Child Matters project in the Philippines.

engagement and collaboration that has generated efforts far beyond what the Sanofi Espoir Foundation could have funded by itself. My Child Matters has also connected health-care professionals and community members from diverse centres in five continents and provided leadership training and networking opportunities to participants.

Capacity building

The most important capacity in any health programme is human capacity, and training and mentoring programmes were part of all My Child Matters projects. The palliative care training provided by these programmes in Bangladesh, Thailand, and Guatemala created a large cohort of professionals with interest in palliative care who gained confidence to effectively manage patients in pain or at the end of life. However, access to opioid pain relief remains problematic in low-income and middle-income countries and is the subject of intense advocacy efforts by local professional organisations, such as the Thai Paediatric Oncology Group in Thailand, and local NGOs such as the ASHIC Foundation in Bangladesh. The training of doctors and nurses to provide oncology care is the focus of several My Child Matters projects, including the African School of Paediatric Oncology, paediatric oncology nurse training in Pakistan, and physician training in Guatemala, and primary care providers' training in early cancer detection, which was coordinated by the Pan-American Health Organization in Colombia and Honduras. An essential complement to training is infrastructure, which includes oncology units with stable funding for key personnel. Accordingly, the Senegal project included not only training, but also included the

renovation of a paediatric oncology ward in which patients can receive specialised nursing care and isolation can be provided for those at risk of infection. The development of the African School of Paediatric Oncology in Morocco created not only a regional hub for trainees, but also a peer network with local NGOs that support oncology programmes in the trainees' countries of origin. Graduates have returned home to strengthen or develop oncology units and address all steps necessary to help improve cancer outcomes, but only because they had the help of local leaders, local NGOs, international collaborators, and their governments.

Government

Government support provided an important impetus towards sustainability in several projects. The standardisation and inclusion of cancer awareness and education campaigns in the public health-care systems of Egypt, Honduras, and Morocco contributed to the early diagnosis of paediatric cancer, and the creation of centres of excellence in public hospitals increased the probability of long-term sustainability and effectiveness of the projects, as was the case with the retinoblastoma programme in Mali. Access to essential chemotherapy through government health insurance for children with acute lymphoblastic leukaemia in the Philippines allowed many more children access to treatment, and a network of public hospitals and satellite clinics to share protocols and expertise contributed to improvements in Thailand, Paraguay, French-speaking African countries, Honduras, and the Philippines. However, in low-income and middle-income countries, the government cannot always be counted on for the sustainability of projects (ie, funding and investment). Therefore, community engagement and the support of NGOs remain essential, as is the case in Venezuela. Although private health insurance plays a growing role in these regions, especially those of middle income, the adoption of health insurance schemes, whether public or private, is on the agenda of many low-income and middle-income countries as a step towards universal health coverage (Sustainable Development Goal 3), which was described as "the linchpin of the health-related sustainable development goals".⁵⁵

Addressing specific causes of treatment failure

We note that addressing the early causes of treatment failure does not necessarily lead to improved outcomes for children with cancer. If access to facilities to make a correct diagnosis increases from 50% to 100%, but the additional 50% of children who were diagnosed do not have access to treatment, survival outcomes would not change. Similarly, if both access to diagnosis and treatment increased to 100%, the influx of new patients could overwhelm the already constrained human and financial resources of an oncology programme and decrease the event-free survival for all (figure 3). We propose that priority should be given to interventions

that target areas where rapid and sustainable improvement in outcomes can be documented that lead to increases in final overall outcomes, not just in one component of it. For example, projects in Nicaragua and Pakistan focused specifically on reducing death related to treatment toxicity by improving infection prevention and control. The momentum achieved by these projects can then be leveraged to mobilise resources for other challenging causes of treatment failure.

Enabling technologies—education, communication, and data management

Enabling technologies played an important role in several projects. The e-learning platform of the African School of Paediatric Oncology allows trainees to review course material from home before coming for in-person training in Morocco and France, and to access new materials after completion of training. E-learning content was developed specifically for health-care providers from French-speaking African countries, and course creators and lecturers have extensive experience in similar settings. The electronic patient registration and follow-up system developed in Paraguay tracks patient appointments, allows call-backs to patients who miss appointments to prevent non-adherence and abandonment, and improves communication among health-care providers at different centres. Finally, real-time discussion of patients' diagnoses and treatment provides invaluable training opportunities for staff, while also improving ongoing patient care. Many groups use Cure4Kids, an online resource by St Jude Children's Research Hospital (Memphis, TN, USA), to facilitate regular case discussions, and a telepathology programme proved to be very effective for real-time consultations that had lasting benefits.⁵⁴ Similarly, Mali retinoblastoma physicians use the ORBIS Cybersight system (London, UK) for case discussions with experts at the Curie Institute, Paris.

Cancer registration at the hospital, regional, and national level has become increasingly common, even in low-income and middle-income countries, and has allowed the assessment of trends to inform health-care policy and support epidemiology studies.^{16,18,32,52,56–63} Treatment abandonment is increasingly reported in hospital-based and population-based registries, and is appropriately considered as a cause of treatment failure in statistical analysis, as well as being included in projects designed to improve outcomes in low-income and middle-income countries.^{16,18,20,64–71} However, population-based registries, and even many hospital-based registries, do not have sufficient detail about the care that is provided to patients, and the outcomes achieved, to guide interventions or to support monitoring and assessment of projects. Until high-quality, real-time, and individual patient data are available to local providers, to guide the care of specific patients and underpin quality improvement efforts, progress in this area will be difficult to measure. At a minimum, patient-level data should

include diagnosis, stage and risk group assignment, treatment protocol, therapy delivered, treatment delays, causes of treatment delays, toxic effects, treatment abandonment, causes of abandonment, death, cause of death, relapse, sites of relapse, adherence, and causes of non-adherence. In this regard, several tools are available at no cost to users: REDCap can be configured to support paediatric oncology data management; the Vigicancer population-based registry in Cali, Colombia, has added clinical and protocol information to include leukaemia protocol information, key toxicities of therapy, and risk factors for abandonment to the registry data already being collected; and the Resonance Patient Center includes a scheduling system that flags patients who miss appointments and has protocol roadmaps, preconfigured analytics, and other tools to facilitate patient care and quality improvement.^{72,73} Universal implementation of integrated data systems that simultaneously meet the needs of patients, clinicians, epidemiologists, NGOs, and governments is urgently needed.²

Ethical issues

Some people question the ethics of investing in childhood cancer care in low-income and middle-income countries, where childhood deaths from malnutrition, diarrhoea, infections, and other common illnesses greatly exceed deaths from cancer, and therefore is considered an unnecessary medical priority. Indeed, if every child younger than 5 years with cancer survived, it would improve under-5 mortality by only 0·2 per 1000 children in low-income and middle-income countries. However, in most low-income and middle-income countries, cancer services are already provided, and optimising these services can save additional lives, often without additional cost especially when expensive or less effective interventions have been prioritised over highly effective, low-cost interventions such as hand hygiene programmes, patient education efforts, subsidised transportation to reach the hospital, and hiring sufficient numbers of nurses and social workers. Furthermore, civil society and external NGOs might contribute substantially to childhood cancer programmes when they would not have contributed to vaccination or clean water efforts. We propose that initial efforts should focus on improving outcomes for the most curable patients who have cancers for which survival outcomes in high-income countries exceeds 90%, while building the infrastructure to help children with all types of illnesses. Such an approach will hopefully lay the foundation for treatment of more advanced cancers in the future.

Conclusion

Oncology care is complex, and each step to help improve outcomes has many obstacles in low-income and middle-income countries. The multifaceted approach of the My Child Matters programme has affected various

For more on REDCap see
<https://www.project-redcap.org/>

For more on Vigicancer see
<http://pohema.org/vigicancer/>

For more on Resonance Patient Center see <https://resonanceoncology.org>

For more on Cure4Kids see
<https://www.Cure4Kids.org>

For more on Cybersight system see <http://www.cybersight.org>

outcome measures, from diagnosis to completion of therapy. This programme will continue to support projects that are catalytic and have a high probability of being sustained and scaled to reach an entire country, as was the case in Paraguay, or a group of countries, as with the GFAOP. Such efforts complement those of government, civil society, the private sector, and others, and outcomes suggest that substantial, sustainable, scalable progress in paediatric oncology is indeed possible in all countries.

Contributors

SCH, AZ, RCR, and AG-L contributed to concept development and manuscript planning. SCH and AZ did the literature research and manuscript writing and revision, with manuscript guidance from RCR and AG-L. SCH, AZ, CGL, RCR, and AG-L designed the study. XC and OW contributed with conceptual input. SCH contributed to data analysis and interpretation, and AZ and CGL contributed to data interpretation. PB, CP, AS, LHa, CM, AP, MH, LHe, SC, LF, MAC, JL, and FT contributed with content and data input. AZ contributed to the creation of the tables and CGL to the creation of the figures, while SCH and XC did so to both figures and tables. XC revised the manuscript. OW, CGL, RCR, and AG-L reviewed and discussed earlier and final drafts of the manuscript. PB, CP, AS, LHa, CM, AP, MH, LHe, SC, LF, MAC, JL, and FT reviewed and discussed the final draft. OW contributed with professional knowledge input. All authors participated in data collection, had access to all the data in the study, and approved the final version before submission.

Declaration of interests

SCH reports grants from Sanofi Espoir Foundation during the conduct of the study. SCH also reports grants and personal fees from Jazz Pharmaceuticals and personal fees from Shire, Sanofi, Sigma Tau, and Alexion, outside the submitted work. AZ reports a grant from Sanofi Espoir Foundation, outside the submitted work. OW and LHa report personal fees from Foundation Sanofi Espoir, during the conduct of the study. AS, CM, AP, MH, and LHe report grants from Sanofi Espoir Foundation, during the conduct of the study. AG-L reports personal fees and other from Sanofi, during the conduct of the study. CGL reports institutional programme support from the My Child Matters Programme during the conduct of the study. XC, PB, CP, SC, LF, MAC, JL, FT, and RCR declare no competing interests.

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