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# My Child Matters Paraguay

Sanofi

Submitted as part of Access Accelerated

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# Program Description

# Program Overview

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## 1 Program Name

My Child Matters - Paraguay

## 2 Diseases program aims to address

- Cancer (Childhood)

## 3 Beneficiary population

- Age: Children (under 5yrs)

## 4 Countries

- Paraguay

## 5 Program start date

January 01, 2009.

## 6 Anticipated program completion date

Completion date not specified.

## 7 Contact person

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## 8 Program summary

My Child Matters (MCM)-Paraguay started in 2009 with the aim of improving access and quality of care for children and adolescents with cancer. MCM-Paraguay has four main components:

1. Decentralized health care delivery through satellite clinics.
2. Provision of social support by a multidisciplinary team.
3. Development of a 'risk of abandonment' assessment tool.
4. Health care provider training in early diagnosis of child cancer.

1. Decentralized health care delivery through satellite clinics:  
Children can be treated as close as possible to their home in 4 regional pediatric clinics for cancer care working in Network. The implementation of a National Network of Pediatric Cancer Care and a decentralized management model has enabled us to decentralize the treatment and follow-up of children with cancer through satellite clinics.<sup>1</sup> This allows for timely access to diagnosis and treatment and contributes to improvement in survival rates in acute Lymphoblastic patients. Analyzing the challenges, success, and the cost-effectiveness of these pediatric cancer regional clinics for referrals and follow-ups, allows us to suggest this as an optimum model to implement within the context of a national network of public health. These clinics could be replicated in other regions, expanding the success achieved and to elaborate training programs to detect and diagnose pediatric cancers, including solid tumors, as well as to develop a program in continuing medical education on this topic.

2. Social support by a multidisciplinary team:  
The program has created a network of social and emotional support for children and families through the following:

- a) strengthening social work services through the creation of a multidisciplinary team of human resources dedicated exclusively to social support services.
- b) Promotion and advocacy, which involve the determination of risk indicators for abandonment
- c) the implementation of certain measures such as appointment scheduling, control of attendance to consultations, phone calls to follow up on patients who do not attend appointments, home visits and also, in some cases, bring legal actions in case of care abandonment. In addition to these services, the program supports a "School for Parents" ("Escuela Para Padres", in Spanish) where parents are trained on many issues related to the practical management of children with cancer.

(Continued on next page)

# Program Overview

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## 8 Program summary, cont.

### 3. Development of a “risk of abandonment” assessment tool:

This program implements a simple and electronic classification tool (i.e. patients are classified based on indicators of risk of abandonment) and then tracks those patients that require it. After a review of the cases of abandonment in previous years, criteria associated with risk of abandonment were established in our hospital, oriented to measure the social and economic vulnerability of patients. The details of this score will be published soon. Subsequently, thanks to the My Child Matters project, a score was created so that during the first patient visit, a patient’s social risks are evaluated and a risk of abandonment score is assigned to the family. Based on our review of the cases of abandonment in previous years and the thesis work of Dr. Angélica Samudio, we have developed this risk of abandonment score that allows us to identify the families with social risk that require more support to carry out the treatment<sup>3</sup>. The advantage of this system is mainly the ease of use of the application and particularly the time-savings in terms of human resources for the achievement of results.

### 4. Health care provider training in early diagnosis of child cancer:

This program includes training health professionals in early diagnosis. Optimization of diagnosis through national training programs for pediatricians, nurses and primary care physicians, in early signs and symptoms of cancer in patients who live in the areas of influence of the satellites clinics, which then facilitates the health providers to provide a referral to the higher-level treatment referral center. Through the program, parents and the community are trained on cancer symptoms and on the care for children with cancer.

In 2016, three new components were added to the initial program, focused on improving care for children with brain tumors:

#### 1. Development of a strategic alliance with local stakeholders:

The program includes activities to strengthen alliances with local authorities, NGOs, private sector, media and others. We consider it important that children with cancer treated in different health systems, can access quality care. This work includes:

- a) Stratification of treatment centers according to their ability to solve the different comprehensive care of the child with cancer.
- b) The institutionalization of the network. We are working on the strengthening of intra-departmental networks of reference and counter-referral. Through a local leader, it will articulate and document the reference and counter-referral traffic of all patients along the network that is reflected at the level of the central leader.
- c) Standardization of practices.
- d) Quality. This initiative has as objective the improvement of care for children and adolescents with cancer.

#### 2. Health care provider training in services for children with brain tumors:

Training of professionals in diagnosis (pediatricians, family physicians), treatment (pathologists, neurosurgeons, oncologists, nurses) and rehabilitation of these patients.

3. Development of a community awareness campaign: As part of this project, we developed an awareness campaign targeting general public, school teachers, and health care providers.

# Program Strategies & Activities

## 9 Strategies and activities

### Strategy 1: Community Awareness and Linkage to Care

ACTIVITY	DESCRIPTION
Planning	Development of a strategic alliance with local stakeholders.
Communication	Implementation of the community campaign to train parents and people to: <ul style="list-style-type: none"> <li>- Recognize critical signs during treatment;</li> <li>- Adopt better health care, hygiene measures and feeding habits.</li> </ul>
Technology	Set up the technologic resources for communication via computers, internet, Microsoft Powerpoint presentations and other channels, such as media, radio, TV and newspapers.
Mobilization	[No response provided]

### Strategy 2: Health Service Strengthening

ACTIVITY	DESCRIPTION
Training	Health care provider training in early diagnosis of child cancer.
Planning	Elaboration of the standards for developing centers of excellence
Infrastructure	Purchasing equipment, computers, video projectors. Improvement of access to internet within the pediatric department and the satellites clinics. Hostels/ lodges are available for parents and patients when they live in rural areas far from the clinics.
Technology	Development of a data registration system and an e-Learning platform.
Management	Improving the allocation of human resources, the development of training sessions and the inter-institutional cooperation.

### Strategy 3: Health Service Delivery

ACTIVITY	DESCRIPTION
Retention	Social support by a multidisciplinary team; development of a 'risk of abandonment' assessment tool.
Treatment	Decentralized health care delivery through satellite clinics.

# Program Strategies & Activities

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## 10 Strategy by country

STRATEGY	COUNTRY
Community Awareness and Linkage to Care	Paraguay
Health Service Strengthening	Paraguay
Health Service Delivery	Paraguay

# Companies, Partners & Stakeholders

## 11 Company roles

COMPANY	ROLE
Sanofi	<ul style="list-style-type: none"> <li>• Program management and coordination.</li> <li>• Organization of the expert committee.</li> <li>• Organization of the scientific overview.</li> <li>• Organization of the mentor-mentee program.</li> <li>• Organization of the scientific sessions in the international congress highlighting the program.</li> <li>• Encouraging the scientific articles on the program.</li> <li>• Encouraging sharing of experiences and best practices.</li> <li>• Organization of training sessions for the project teams.</li> <li>• Encouraging south-south exchanges and support.</li> <li>• Communication.</li> <li>• Funding.</li> </ul>

## 12 Funding and implementing partners

PARTNER	ROLE/URL	SECTOR
Ministry of Public Health and Social Welfare	<p>The Ministry of Health is responsible for national policies. The satellite clinics of the National Child Cancer Care Network are housed in Regional Hospitals of the Ministry of Public Health and Social Welfare, important for the sustainability of the project.</p> <p><a href="https://www.mspbs.gov.py/portal">https://www.mspbs.gov.py/portal</a></p>	Public
Pediatric Hematology and Oncology Department – National University of Asuncion	<p>The Pediatric Hemato-Oncology Department of the Hospital de Clínicas of the National University of Asunción is the reference center of the National Child Cancer Care Network. It has become a center of excellence for the treatment of pediatric patients with cancer. Hosting national team trainers, and together with local teams, it performs the regional attentions in satellite clinics. Professor Angélica Samudio is the general coordinator of the project. Dr. Diego Figueredo from Hematología Oncología PEdiatria (HOPE) unit is responsible for the care at the Satellite clinic of the North Region. Dr. Jazmin Servin is responsible for the Satellite Clinic of the Middle Region. Dr. Isabel Mattio is responsible for the Satellite Clinic of the Southern region. Dr. Delia Guillen is responsible for the Eastern region.</p> <p><a href="http://www.una.py/">http://www.una.py/</a></p>	Public
ReNACI Foundation	<p>Non-Governmental Organization (NGO). Dedicated to the research and the aid of pediatric patients with hemato-oncologic pathologies in Paraguay. National Responsible for project management.</p> <p><a href="http://www.fundacionrenaci.org.py/">http://www.fundacionrenaci.org.py/</a></p>	Voluntary



# Companies, Partners & Stakeholders

## 13 Funding and implementing partners by country

PARTNER	COUNTRY
Ministry of Public Health and Social Welfare	Paraguay
Pediatric Hematology and Oncology Department – National University of Asuncion	Paraguay
ReNACI Foundation	Paraguay

## 14 Stakeholders

STAKEHOLDER	DESCRIPTION OF ENGAGEMENT
Government	We have regular advocacy meetings with the national authorities, the Ministry of Health, political leaders and regional authorities.
NGO	We have partnered with local NGOs to sponsor programs aligned to MCM-Paraguay.
Local Universities	As the pediatric cancer center of reference for this program is located in the Clinical Hospital of The National University of Asuncion, local universities and academia are part of our engagement strategies.
Local Hospitals/ Health Facilities	Regional hospitals of the Ministry of Health are part of the network, they house the satellite clinics.

# Local Context, Equity & Sustainability

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## 15 Local health needs addressed by program

The gross national income per capita in Paraguay is US\$ 4,040, which is lower than that of other countries in Latin America and the Caribbean<sup>4</sup>. It has a population of 6,783,374 (D.G.E.E.C 2013) and 32% of the population is less than 15 years old (2,187,812). The mortality rate for children under-5 years old is 22 per 1,000 live births, and 23% of the population is living below the national poverty line, while 30% has no access to healthcare<sup>5</sup>. The estimated yearly incidence of childhood cancer in Paraguay is 7.5 cases per 100,000 children aged 0 to 14 years, and cancer is the second-leading cause of death in children aged 5 to 19 years.<sup>6-9</sup>

Until 2009, children with cancer in Paraguay were diagnosed and treated in 1 of the 4 pediatric cancer centers (PCCs) within the Gran Asunción metropolitan area. These PCCs were hampered by several challenges: insufficient number of trained personnel; insufficient treatment supplies including chemotherapeutic agents, antibiotics, and basic supplies for administration; insufficient diagnostic laboratory resources; and limited space for patient care and family housing. In 2009, a pediatric cancer network was implemented in Paraguay under the auspice of My Child Matters (Sanofi Espoir Program). The Pediatric Cancer Center (PCC) of the National University of Asunción School of Medicine (SM) managed the Childhood Cancer Care Network.

The National University of Asunción Department of Pediatric Hematology-oncology is one of the centers of reference for childhood cancer in Paraguay. It is within the School of Medicine of the National University of Asunción. From its beginnings in 1987, it was the first center in the country that treated children with hematology and oncology problems both benign and malignant. Until 2012, the PCC was funded by the Pediatrics Department of National University of Asunción School of Medicine. The goal of this network was to decentralize care of children with cancer by establishing and sustaining four regional pediatric clinics for early cancer detection, referral, treatment, social assistance and follow-up of pediatrics patients with cancer. During the network's first years, two regional pediatric clinics (Ciudad del Este in the eastern region and Coronel Oviedo in the middle region) were established as part of the national health system with the support of the Ministry of Health. In 2010, the PCC-SM team established care centers in the northern (city of Pedro Juan Caballero) and southern (city of San Juan Bautista) regions of Paraguay. For the next two years (2011 and 2012), the network devoted its efforts to strengthening the regional teams' activities and standardizing the PCC-SM's mentoring roles and referrals.

The PCC-SM leadership began its plan to sustain the regional clinics by negotiating the incorporation of these clinics into Paraguay's national health care system. Currently, one oncologist, three pediatricians, four nurses, and four administrative personnel run the clinics. The Network has improved access to care, social support and adherence to treatment of patients with cancer in Paraguay. Major improvement stimulated by the PCC-SM, resulted in the development of a center of excellence for comprehensive cancer care. This allowed the establishment of a social support network for the child and his/her family, from diagnosis to the end of treatment. In turn, this model serves as a national health network for diagnosis and referral of pediatric patients with hematologic or oncologic diseases. Through the implementation of a network with reference centers and satellite clinics distributed throughout the country's regions, the system offers accessible hospital services. This is supported by an established system of reference and counter reference that facilitates referral of patients with suspected cancer to a specialized center.

The current focus of the program is the treatment of brain tumors. This is a challenging area particularly in developing countries, as it requires specialists and services with a high level of expertise, continuing medical education and updates on current cancer treatments. By expanding the reach of the program to solid tumors, MCM-Paraguay program will be able to improve quality of life for a larger number of Paraguayan children. By networking with centers of excellence based on international standards, MCM-Paraguay intends to move forward with universal access to education and healthcare free of charge for catastrophic illnesses through the state.

The new project will work to develop strategic alliances with local authorities, NGOs, private sector, media and others.

# Local Context, Equity & Sustainability

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## 15 Local health needs addressed by program, cont.

### a How needs were assessed

[ No answer provided]

### b Formal needs assessment conducted

[ No answer provided]

## 16 Social inequity addressed

Yes, this program aims to address social inequity which affects access to health care. Cancer is a costly disease, in particular in developing countries where geographic and transportation barriers are large.<sup>10,11</sup> The efforts contained in this program are valuable because even when treatment costs are covered, the cost of access to care - including travel, lodging and lost wages - can still be a major obstacle to obtaining supportive care, especially for disadvantaged and rural populations.<sup>12</sup> Creating a network of health services with rural reach is of utmost importance, because pediatric cancer in Paraguay is a public health problem and a social problem. From a public health perspective, the health system in Paraguay is fragmented and segmented. There are insufficient health policies, limited resources and limited cancer information and promotion for the community, leading to delayed access to diagnosis and care. It also encompasses a social problem due to the regressive impacts of difficult access to pediatric cancer centers. Limited housing for out of town patients and their families, leads to breaking-down of families' structure and a high rate of child abandonment.

## 17 Local policies, practices, and laws considered during program design

The program is consistent with Paraguay's guidelines on cancer management and regulations for education of health professionals. The program objectives and activities are aligned to the fundamental aims enshrined in the legislation defining the National Health System (Law 1032/1996).<sup>13</sup> This involves the expansion of public coverage, strengthening of health system infrastructure at national and local levels, and the improvement of access. In making care more accessible, efforts in our program include both structural and operational strategies. These are respectively, the creation of regional clinics to be closer to rural communities<sup>12</sup> and development of integrated networks of care, referrals and communication.

## 18 How diversion of resources from other public health priorities is avoided

[No answer provided]

# Local Context, Equity & Sustainability

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19 Program provides health technologies (medical devices, medicines, and vaccines)

[No response provided]

20 Health technology(ies) are part of local standard treatment guidelines

N/A

21 Health technologies are covered by local health insurance schemes

N/A

22 Program provides medicines listed on the National Essential Medicines List

N/A

23 Sustainability plan

Political commitment of the authorities and decision-makers will ensure the sustainability of the project. The awareness of the government authorities and the commitment of the Ministry of Health, allowed inclusion of cancer as a health policy agenda priority, which guarantees future sustainability. The Childhood Cancer Care Network, established thanks to My Child Matters - Paraguay program, was declared to be of National Interest by the Decree Number: 2739 of August 18th, 2009 by the President of the Republic of Paraguay.

# Additional Program Information

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## 24 Additional program information

After 9 years of joint work, the testimonials show that there is a 'before' and an 'after' My Child Matters. The difference between yesterday and today is enormous: before, 7 out of 10 children abandoned their treatment and the cure rate did not exceed 20%. Today, abandonment has plummeted to 0, no child leaves the treatment. Access to integral care is given to 100% and the cure rate reaches 70%.<sup>1-3</sup>

### a Potential conflict of interest discussed with government entity

[ No answer provided]

## 25 Access Accelerated Initiative participant

Yes.

## 26 International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) membership

Yes.

# Resources

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# Program Indicators

## PROGRAM NAME

# My Child Matters - Paraguay

## 27 List of indicator data to be reported into Access Observatory database

INDICATOR	TYPE	STRATEGY	2008-2011	2008	2009	2010	2011	2012
1 Value of resources	Input	All Program Strategies	\$196,369.75	---	---	---	---	---
2 Patients with complete cancer remission	Impact	All Program Strategies	---	23 people	32 people	32 people	46 people	40 people
3 Patients retained in care	Outcome	Health Service Strengthening	---	---	---	---	---	---
4 Number of people trained	Output	Health Service Strengthening	---	---	---	---	---	---
5 Number of diagnosed cases at early stages	Outcome	Health Service Strengthening	---	---	---	---	---	---
6 Number of diagnosed cases	Impact	All Program Strategies	---	37 people	45 people	45 people	30 people	47 people
7 Communication materials in use	Output	Community Awareness and Linkage to Care	---	---	---	---	---	---
8 Number of patients on treatment	Outcome	Health Service Delivery	---	---	---	---	---	---
9 Sites in use	Output	Health Service	---	---	---	---	---	---



## PROGRAM NAME

# My Child Matters - Paraguay

## 27 List of indicator data to be reported into Access Observatory database, cont.

INDICATOR	TYPE	STRATEGY	2013-2015	2016	2017	2018	2019	2020
1 Value of resources	Input	All Program Strategies	\$165,686.98	---	---	€ 70,000	€ 80,600	€ 96,700
2 Patients with complete cancer remission	Impact	All Program Strategies	---	---	---	93 people	86 people	62 people
3 Patients retained in care	Outcome	Health Service Strengthening	---	---	---	100 %	98 %	96%
4 Number of people trained	Output	Health Service Strengthening	---	55 people	647 people	209 people	711 people	575 people
5 Number of diagnosed cases at early stages	Outcome	Health Service Strengthening	---	---	---	80 people	78 people	60 people
6 Number of diagnosed cases	Impact	All Program Strategies	---	---	---	102 people	98 people	75 people
7 Communication materials in use	Output	Community Awareness and Linkage to Care	---	---	17 tools	3 tools	58 tools	21 tools
8 Number of patients on treatment	Outcome	Health Service Delivery	---	38 people	---	102 people	97 people	72 people
9 Sites in use	Output	Health Service	---	---	5 sites	5 sites	5 sites	5 sites

ITEM	DESCRIPTION
Definition	Total expenditure by company to operate program, including all expenditures that can reasonably be defined as necessary to operate the program
Method of measurement	Program administrative records or accounting or tax records provide details in the expenditures on the program in a defined period of time  Calculation: Sum of expenditures (e.g., staff, materials) on program in US \$
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Sanofi	A member of the Sanofi Espoir Foundation team records the payment of the grant allocated for 3 years.	Every 3 years
31 Data processing	Sanofi	The project and associated budget plans are submitted and agreed by an experts committee for 3 years. Every year the project progress is then reviewed by the same committee who decide maintaining or re-adjusting the funding. Then a member of The Sanofi Espoir Foundation keeps records of money distributed for the program every year.	Once per year
32 Data validation		A member of the local team reports performed activities and objectives every year. Members of the expert committee then review the budget allocation according to the agreed objectives.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2008-2011	2013-2015	2017	2018	2019	2020
1 Value of resources	\$196,369.75	\$165,686.98	---	€ 70,000	€ 80,600	€ 96,700

Comments: 2008-2011; 2013-2015: No year-specific data available.

ITEM	DESCRIPTION
Definition	Number of treated surviving children diagnosed with cancer showing a complete remission
Method of measurement	Number of treated surviving children over total number of diagnosed children
28 Data source	Routine program data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The doctors of the local team check and register clinical and follow-up data of children with cancer into the electronic registration system.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	A member of the local team counts the number of surviving children diagnosed with cancer showing a complete remission.	Once per year
32 Data validation		The project coordinator reviews the clinical and follow-up data of children with cancer from the electronic registration system.	

33 Challenges in data collection and steps to address challenges

It is possible that some loss to follow up of the children diagnosed with cancer impacts the patient’s number with complete remission.

INDICATOR	2008	2009	2010	2011	2012	2017	2018	2019	2020
2 Patients with complete cancer remission	23 people	32 people	32 people	46 people	40 people	---	93 people	86 people	62 people

Comments: 2008 -2012: Data correspond to acute lymphoid leukemia cases.

ITEM	DESCRIPTION
Definition	Percentage of registered patients who had a facility visit out of total number of registered patients expected to receive treatment for a specific condition within that time period (e.g. month)
Method of measurement	The health facility patient registry should provide information on the number of patient registered with the health facility  Calculation: $\frac{\text{Number of registered patients attending the point of care}}{\text{Number of registered patients expected to attend within that time period.}} \times 100$
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The doctors of the local team check and register the clinical data routinely and check the data quality before registering them into the electronic registration system.	Ongoing
31 Data processing	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción; ReNACI Foundation	The project coordinator reports from data registration system the number of patients who got access to care versus the number of patients expected to attend the care.	Once per year
32 Data validation		No implemented process.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2017	2018	2019	2020
3 Patients retained in care	---	100%	98%	96%

Comments: 2018: Numerator: 102, Denominator: 102; 2019: Numerator:97, Denominator: 98; 2020: Numerator: 72, Denominator: 75.

ITEM	DESCRIPTION
Definition	Number of trainees
Method of measurement	Counting of people who completed all training requirements Calculation: Sum of the number of people trained
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local team; Pediatric Hematology and Oncology Department – National University of Asunción	The human resources local team organizes trainings in ReNACI clinics on topics such as centralized patient care, continuing education, early diagnostic and research (e-learning platform and workshop). A member of the local team keeps a register of participants at these trainings.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	Once a year, a member of the local team aggregates the number of professionals participating in the Human Resource Training and Health Professionals workshops in ReNACI clinics and sends the report to Sanofi Espoir Foundation.	Once per year
32 Data validation		No implemented process.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2016	2017	2018	2019	2020
4 Number of people trained	55 people	647 people	209 people	711 people	575 people

Comments: 2016: Data correspond to workshop participants; 2018: 209 health care professionals trained + 119 parents trained; 2019: 711 health care professionals trained + 100 parents trained; 2020: Health professionals: 419 + 156 parents.

INDICATOR **Number of diagnosed cases at early stages**

STRATEGY HEALTH SERVICE STRENGTHENING

# 5

ITEM	DESCRIPTION
Definition	Number of children diagnosed with cancer at early stage
Method of measurement	Number of diagnostic at early stage over all cancer diagnosed
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The doctors of the local team check and register clinical and follow-up data of early diagnosed childhood cancer cases into the electronic registration system.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	Once a year, a member of the local team counts the number of children diagnosed with cancer at early stage in the past year from the electronic registration system records.	Once per year
32 Data validation		The project coordinator reviews the clinical and follow-up data of children with cancer from the electronic registration system.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2017	2018	2019	2020
5 Number of diagnosed cases at early stages	---	80 people	78 people	60 people

Comments: N/A.

INDICATOR **Number of diagnosed cases**

STRATEGY HEALTH SERVICE STRENGTHENING

6

ITEM	DESCRIPTION
Definition	Number of children with cancer
Method of measurement	Counting of diagnosed children with cancer
28 Data source	Routine program data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The doctors of the local team check and register clinical and follow-up data of diagnosed childhood cancer cases from the electronic registration system.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	Once a year, a member of the local team counts the number of children diagnosed with cancer in the past year from the electronic registration system records.	Once per year
32 Data validation		The project coordinator reviews the clinical and follow-up data of children with cancer from the electronic registration system.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2008	2009	2010	2011	2012	2017	2018	2019	2020
6 Number of diagnosed cases	37 people	45 people	45 people	30 people	47 cases	---	102 people	98 people	75 people

Comments: 2008-2012: Data correspond to acute lymphoid leukemia cases; 2018: 102 cancer diagnosed on 530 new patients (the rest: benign Hematological or non-oncological); 2019: 98 cancer diagnosed on 422 new patients (the rest: 157 Benign Hematological and 167 Non-oncological).

ITEM	DESCRIPTION
Definition	Number of communication materials introduced and in use by the program
Method of measurement	Counting the number of communication materials created and in use by the program Calculation: Sum of communication materials created by the program
Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The local team created posters, media publications, video, flyers, and online materials for sensitizing locals to cancer healthcare ReNACI (Red Nacional de Cáncer Infantil) system.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	A member of the local team sums the number of communication tools created in the past year based on their records and report the number to Sanofi Espoir Foundation.	Ongoing
Data validation		No implemented procedure.	

33 Challenges in data collection and steps to address challenges

It could be difficult to gather all the communication ways such as media and social networks.

INDICATOR	2017	2018	2019	2020
7 Communication materials in use	17 tools	3 tools	58 tools	21 tools

Comments: 2017: Data correspond to articles published on Paraguay journals websites. 2018: Press publications (53) + distributed folders / educational material (1000) + social media; 2018: Press publications (53) + distributed folders / educational material (1000) + social media; 2019: Mobile phone application, Press vouchers, Social Media: Facebook: @fundacionrenaci; Twitter: @renacipy; Instagram: renacipy; 2020: 16 Articles published on Paraguay journals websites + 5 Distributed folders / educational material. Social Media: Facebook: @fundacionrenaci Twitter: @renacipy Instagram: renacipy



ITEM	DESCRIPTION
Definition	Number of patients that have received treatment through the program.
Method of measurement	Counting of people who received treatment through the program Calculation: Sum of the number of people treated
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The doctors of the local team check and register the clinical data routinely and check the data quality before registering them into the electronic registration system.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	Once a year, a member of the local team aggregates from data registration system the number of children with cancer that are on treatment during the year.	Once per year
32 Data validation		No implemented process.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2016	2017	2018	2019	2020
8 Number of patients on treatment	38 people	---	102 people	97 people	72 people

Comments: N/A

ITEM	DESCRIPTION
Definition	Number of facilities where the services are offered.
Method of measurement	The number of facilities or infrastructure units which are in use and where services are offered  Calculation: Sum of the numerical count of facilities or infrastructure units where services are offered
28 Data source	Routine program data.
29 Frequency of reporting	Once per year.

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Local medical team; Pediatric Hematology and Oncology Department – National University of Asunción	The pediatric cancer (PCC) of National University of Asuncion School of Medicine in collaboration with health authorities manages the Childhood Cancer Care Network ReNACI. This network led to decentralized care of children with cancer by establishing and sustaining regional satellite pediatric clinics for early cancer detection, referral, treatment, social assistance and follow-up of pediatrics patients with cancer. The local project coordinator keeps record of the facilities in this network.	Ongoing
31 Data processing	Local medical team; ReNACI Foundation; Pediatric Hematology and Oncology Department – National University of Asunción	A member of the local team aggregates and reports the number of operational satellites infrastructures dedicated to childhood cancer belonging to the ReNACI clinics network every year.	Once per year
32 Data validation		No implemented process.	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2008-2017	2017	2018	2019	2020
9 Sites in use	5 sites	5 sites	5 sites	5 sites	5 sites

Comments: 2018- 2020: 1 Hope Foundation for Cancer Care + 4 satellite clinics; 2019: 5 (HOPE and 4 Satellite Clinics) 10747 consultations (9791 HOPE - 956 Satellite Clinics).

# Program Documents

# Program Documents

1. Sanofi Espoir Foundation. My Child Matters brochure. (2015). Available at: <https://bit.ly/mychildmatters>
2. Baskin, JL., Lezcano, E., Kim BS., et al. Management of children with brain tumours in Paraguay. Neuro-Oncology (2012); 15(2): 235–241. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3548583/pdf/nos291.pdf>
3. Samudio, A., Figueredo, D., Lassaletta, A., et al. Building a national pediatric cancer center and network in Paraguay: lessons for addressing challenges in low income country. J Pediatr Hematol Oncol (2015); 00: 1-8. Available at: [https://journals.lww.com/jpho-online/Abstract/2015/07000/Building\\_a\\_National\\_Pediatric\\_Cancer\\_Center\\_and.9.aspx](https://journals.lww.com/jpho-online/Abstract/2015/07000/Building_a_National_Pediatric_Cancer_Center_and.9.aspx)
4. The UICC My Child Matters initiative awards: combating cancer in children in the developing world. Lancet Oncol (2006), 7(1): 13-14. Available at: <http://forms.uicc.org/templates/uicc/pdf/icf/lancet.pdf>
5. UICC My Child Matters awards: 2006 winners. Lancet Oncol (2007); 8(2): 99. Available at: <https://www.thelancet.com/journals/lanonc/article/PIIS1470204506709822/fulltext>
6. Special Report: International - The My Child Matters Awards: new funding, new countries, new hope. Lancet Oncol (2009); 10(3): 216-217. Available at: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(09\)70001-4/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(09)70001-4/fulltext)
7. Income matters: reducing the mortality gap. Lancet Oncol (2008); 9: 703-704. Available at: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(08\)70186-4/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(08)70186-4/fulltext)
8. Ribeiro, R., Steliarova-Foucher, E., Magrath, I., et al. Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. Lancet Oncol (2008); 9:721–29. Available at: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(08\)70194-3/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(08)70194-3/fulltext)

# Appendix

This program report is based on the information gathered from the Access Observatory questionnaire below.

## Program Description

### PROGRAM OVERVIEW

#### 1 Program Name

#### 2 Diseases program aims to address:

Please identify the disease(s) that your program aims to address (select all that apply).

#### 3 Beneficiary population

Please identify the beneficiary population of this program (select all that apply).

#### 4 Countries

Please select all countries that this program is being implemented in (select all that apply).

#### 5 Program Start Date

#### 6 Anticipated Program Completion Date

#### 7 Contact person

On the public profile for this program, if you would like to display a contact person for this program, please list the name and email address here (i.e. someone from the public could email with questions about this program profile and data).

#### 8 Program summary

Please provide a brief summary of your program including program objectives (e.g., the intended purposes and expected results of the program; if a pilot program, please note this). Please provide a URL, if available. Please limit replies to 750 words.

### PROGRAM STRATEGIES & ACTIVITIES

#### 9 Strategies and activities

Based on the BUSPH Taxonomy of Strategies, which strategy or strategies apply to your program (please select all that apply)?

#### 10 Strategy by country

If you have registered one program for multiple countries, this question allows you to provide a bit more specificity about each country (e.g. some countries have different strategies, diseases, partners, etc.). Please complete these tables as applicable. For each portion you have you selected from above (program strategies), please identify which country/countries these apply.

### COMPANIES, PARTNERS AND STAKEHOLDERS

#### 11 Company roles

Please identify all pharmaceutical companies, including yours, who are collaborating on this program:

What role does each company play in the implementation of your program?

#### 12 Funding and implementing partners

Please identify all funding and implementing partners who are supporting the implementation of this program (Implementing partners is defined as either an associate government or non-government entity or agency that supplements the works of a larger organization or agency by helping to carry out institutional arrangements in line with the larger organization's goals and objectives.)

a. What role does each partner play in the implementation of your program? Please give background on the organization and describe the nature of the relationship between the organization and your company. Describe the local team's responsibilities for the program, with reference to the program strategies and activities. (response required for each partner selected).

b. For each partner, please categorize them as either a Public Sector, Private Sector, or Voluntary Sector partner. (Public Sector is defined as government; Private Sector is defined

as a business unit established, owned, and operated by private individuals for profit, instead of by or for any government or its agencies. Generation and return of profit to its owners or shareholders is emphasized; Voluntary Sector is defined as Organizations whose purpose is to benefit and enrich society, often without profit as a motive and with little or no government intervention. Unlike the private sector where the generation and return of profit to its owners is emphasized, money raised or earned by an organization in the voluntary sector is usually invested back into the community or the organization itself (ex. Charities, foundations, advocacy groups etc.)

c. Please provide the URL to the partner organizations' webpages

### 13 Funding and implementing partners by country

If you have registered one program for multiple countries, this question allows you to provide a bit more specificity about each country (e.g., some countries have different strategies, diseases, partners, etc.). Please complete these tables as applicable. For each portion you have selected from above (funding and implementing partners), please identify which country/countries these apply.

### 14 Stakeholders

Please describe how you have engaged with any of these local stakeholders in the planning and/or implementation of this program. (Stakeholders defined as individuals or entities who are involved in or affected by the execution or outcome of a project and may have influence and authority to dictate whether a project is a success or not (ex. Ministry of Health, NGO, Faith-based organization, etc.). Select all that apply.

- Government, please explain
- Non-Government Organization (NGO), please explain
- Faith-based organization, please explain
- Commercial sector, please explain
- Local hospitals/health facilities, please explain
- Local universities, please explain
- Other, please explain

## LOCAL CONTEXT, EQUITY & SUSTAINABILITY

### 15 Local health needs addressed by program

Please describe how your program is responsive to local health needs and challenges (e.g., how you decided and worked together with local partners to determine that this program was appropriate for this context)?

#### a How were needs assessed

#### b Was a formal need assessment conducted

(Yes/No) If yes, please upload file or provide URL.

### 16 Social inequity addressed

Does your program aim to address social inequity in any way (if yes, please explain). (Inequity is defined as lack of fairness or justice. Sometime 'social disparities,' 'structural barriers' and 'oppression and discrimination' are used to describe the same phenomenon. In social sciences and public health social inequities refer to the systematic lack of fairness or justice related to gender, ethnicity, geographical location and religion. These unequal social relations and structures of power operate to produce experiences of inequitable health outcomes, treatment and access to care. Health and social programs are often designed with the aim to address the lack of fairness and adjust for these systematic failures of systems or policies.\*)

\*Reference: The definition was adapted from Ingram R et al. Social Inequities and Mental Health: A Scoping Review. Vancouver: Study for Gender Inequities and Mental Health, 2013.

### 17 Local policies, practices, and laws considered during program design

How have local policies, practices, and laws (e.g., infrastructure development regulations, education requirements, etc.) been taken into consideration when designing the program?

### 18 How diversion of resources from other public health priorities is avoided

Please explain how the program avoids diverting resources away from other public health priorities? (e.g. local human resources involved in program implementation diverted from other programs or activities).

### 19 Program provides health technologies

Does your program include health technologies (health technologies include medical devices, medicines, and vaccines developed to solve a health problem and improve quality of lives)? (Yes/No)

### 20 Health technology(ies) are part of local standard treatment guidelines

Are the health technology(ies) which are part of your program part of local standard treatment guidelines? (Yes/No) If not, what was the local need for these technologies?

**21** Health technologies are covered by local health insurance schemes

Does your program include health technologies that are covered by local health insurance schemes? (Yes/No) If not, what are the local needs for these technologies?

**22** Program provides medicines listed on the National Essential Medicines List

Does your program include medicines that are listed on the National Essential Medicines List? (Yes/No) If not, what was the local need for these technologies?

**23** Sustainability plan

If applicable, please describe how you have planned for sustainability of the implementation of your program (ex. Creating a transition plan from your company to the local government during the development of the program).

## ADDITIONAL PROGRAM INFORMATION

**24** Additional program information

Is there any additional information that you would like to add about your program that has not been collected in other sections of the form?

**a** Potential conflict of interest discussed with government entity

Have you discussed with governmental entity potential conflicts of interest between the social aims of your program and your business activities? (Yes/No) If yes, please provide more details and the name of the government entity.

**25** Access Accelerated Initiative participant

Is this program part of the Access Accelerated Initiative? (Yes/No)

**26** International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) membership

Is your company a member of the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)? (Yes/No)

## Program Indicators

### INDICATOR DESCRIPTION

**27** List of indicator data to be reported into Access Observatory database

For this program, activities, please select all inputs and impacts for which you plan to collect and report data into this database.

**28** Data source

For this indicator, please select the data source(s) you will rely on.

**29** Frequency of reporting

Indicate the frequency with which data for this indicator can be submitted to the Observatory.

**30** Data collection

- Responsible party: For this indicator, please indicate the party/parties responsible for data collection.
- Data collection — Description: Please briefly describe the data source and collection procedure in detail.
- Data collection — Frequency: For this indicator, please indicate the frequency of data collection.

**31** Data processing

- Responsible party: Please indicate all parties that conduct any processing of this data.
- Data processing— Description: Please briefly describe all processing procedures the data go through. Be explicit in describing the procedures, who enacts them, and the frequency of processing.
- Data processing — Frequency: What is the frequency with which this data is processed?

**32** Data validation

Description: Describe the process (if any) your company uses to validate the quality of the data sent from the local team.

**33** Challenges in data collection and steps to address challenges

Please indicate any challenges that you have in collecting data for this indicator and what you are doing to address those challenges.

# Company-submitted Situation Analysis

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1. Ribeiro, R., Steliarova-Foucher, E., Magrath, I., et al. Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. *Lancet Oncol* 2008; 9:721–29.

URL: <https://www.sciencedirect.com/science/article/pii/S1470204508701943>

2. Baskin, JL., Lezcano, E., Kim BS., et al. Management of children with brain tumours in Paraguay. *Neuro-Oncology* 2013; 15(2): 235–241.

URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3548583/>



