PROGRAM REPORT

PROGRAM ENDED IN 2018

My Child Matters Retinoblastoma

Sanofi

Submitted as part of Access Accelerated

Access Observatory

PROGRAM ENDED IN 2018

Contents

The information in this report has been submitted by the company concerned to the Access Observatory as part of its commitment to Access Accelerated. The information will be updated regularly. For more information about the Access Observatory go to www.accessobservatory.org

Program Description

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Program Overview

1 Program Name

My Child Matters- Retinoblastoma

2 Diseases program aims to address

- Cancer (Childhood)

3 Beneficiary population

- Children (under 5yrs)
- Youth (5-18yrs)
- People with low income
- Rural Populations

4 Countries

- Cte d'Ivoire
- Democratic Republic of the Congo
- Madagascar
- Mali
- Senegal

5 Program start date

November 01, 2011

6 Anticipated program completion date

[Program ended in 2018]

7 Contact person

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8 Program summary

Retinoblastoma (Rb) is a rare (sometimes hereditary) tumour of the retina occurring in young children and affecting both eyes in 30 to 40% of cases.[1,2] Cure is possible in almost 100% of cases in developed countries if patients are diagnosed early and treated appropriately.[3 - 5] The outcome for this disease is poor in developing countries due to late diagnosis, and treatment abandonment especially due to poor acceptance of enucleation as a lifesaving procedure.[6 - 8]

Our project aims to disseminate knowledge about curability of this disease as well as potential for vision salvage through early diagnosis, institution of local control ocular therapies like laser therapy, and rehabilitation with ocular prosthesis after enucleation. For bilateral cases, preservation of useful vision in at least one eye is the goal, and is possible through coordinated teaching, training and enhancement of skill of locally available multidisciplinary team.

Our objective is to demonstrate that a non-costly treatment is effective for saving lives and useful vision in children with Rb, and to convince the government to cover the treatment expenses.

The annual incidence of Rb is about 35 new cases in Senegal, 35-40 in Mali and in Ivory Coast, 55-60 in Madagascar, and 150 in DR Congo. The program trains ophthalmologists, prosthetists, and pathologists on the diagnosis and management of retinoblastoma, including the use of laser therapy in the conservative management of retinoblastoma. Our efforts in this direction have started showing successful results as could be seen in the recently treated bilateral retinoblastoma cases in Mali, Ivory Coast and Senegal.

The Curie Institute, Paris, the referral Institute for the conservative treatment of Rb from all over France, is involved in the laser treatment in this project. The ophthalmologists have been trained in laser treatment in the ophthalmology department of Institute Curie (Dr Laurence Desjardins) and are also trained in research (Dr Keita from the pathology department of university hospital in Bamako in research Center of Institute Curie.

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Program Overview

8 Program summary cont.

The program started in 2011 with the team (pediatric oncologist and ophthalmologist) from Bamako (Mali). It was implemented in countries with a pediatric oncology pilot unit supported by the GFAOP (Franco-African Group of Pediatric Oncology), first in Bamako in November 2011, then in Lubumbashi (DR Congo) in December 2012, in Dakar (Senegal) and Abidjan (Ivory Coast) in November 2013 and finally in Antananarivo (Madagascar) in December 2014.

The main objectives were:

- Improve early diagnosis by information/sensitization of health actors and of the general population
- Ensure an efficient response at all the steps of the care of children: limited delays for 1st consultation, examination under general anesthesia, surgery, access to chemotherapy (given by GFAOP), systematic prosthesis after enucleation, and access to conservative treatments as soon as possible.
- Facilitate retinoblastoma research and registration of all retinoblastoma cases.

A new extension of this project has been added in 2017 in the frame of Accelerated Access Initiative to make the conservative treatment available for bilateral Rb in Senegal, and preserve a useful vision in at least on eye.

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Program Strategies & Activities

9 Strategies and activities

Strategy 1: Community Awareness and Linkage to Care

ACTIVITY	DESCRIPTION
Communication	Disseminate information about the signs of retinoblastoma in order to improve early diagnosis.
Funding	[No response provided]

Strategy 2: Health Service Strengthening

ACTIVITY	DESCRIPTION
Training	Train ophthalmologists, prosthetists, and pathologists in the diagnosis and management of retinoblastoma including the use of laser therapy (conservative treatment) in the management of retinoblastoma.
Technology	Use laser therapy in the conservative treatment of retinoblastoma.
Management	Share treatment protocols.
Funding	[No response provided]

Strategy 3: Health Service Delivery

ACTIVITY	DESCRIPTION
Treatment	Pay part of the cost of treatment for the poorest families.

10 Strategy by country

STRATEGY	COUNTRY
Community Awareness and Linkage to Care	[No response provided]
Health Service Strengthening	[No response provided]
Health Service Delivery	[No response provided]

Companies, Partners & Stakeholders

11 Company roles

COMPANY	ROLE
Sanofi	• Initiative and creation of the program. • Program management and coordination. • Organization of the expert committee. • Organization of the scientific overview. • Organization of the mentor-mentee program. • Organization of the scientific sessions in the international congress highlighting the program. • Encouraging the writing of scientific articles on the program. • Encouraging sharing of experiences and best practices. • Organization of training sessions for the project teams. • Encouraging south-south exchanges. • Communication. • Funding.

12 Funding and implementing partners

PARTNER	ROLE/URL	SECTOR
AMCC (Alliance Mondiale Contre le Cancer)	Coordinator of this project. www.cancer-amcc.org	Voluntary
Curie Institute (Paris, France)	The referent center for conservative treatment in retinoblastoma in France through the expertise of the head of ophthalmology department and the support of the retinoblastoma team of Curie Institute. https://curie.fr	Private
French Ministry of Health	Support partnerships between Curie Institute and Hospitals in Bamako (Institut d'Ophtalmologie Tropicale de l'Afrique, IOTA in 2011 and Gabriel Toure University Hospital in 2012). https://www.has-sante.fr/portail/jcms/r_1455081/en/home-page?portal=r_1455081	Public
GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie)	Support pediatric oncology units in the countries and supply cancer medicines (on essential medicines list) to hospitals. www.gfaop.org	Voluntary
Prothelem	Private lab for eye prostheses: training for the local prosteses makers in Africa. http://www.prothelem.fr/	Private

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Companies, Partners & Stakeholders

Public Hospitals	Providing some materials for the treatment.	Public
Private Funders: Retinostop association; Local associations or foundations (in Abidjan, in Lubumbashi)	Provide funding for the materials used in treatment and rehabilitation.	Private

13 Funding and implementing partners by country

PARTNER	COUNTRY
AMCC (Alliance Mondiale Contre le Cancer)	[No response provided]
Curie Institute (Paris, France)	[No response provided]
French Ministry of Health	[No response provided]
GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie)	[No response provided]
Prothelem	[No response provided]
Public Hospitals	[No response provided]
Private Funders: Retinostop association; Local associations or foundations (in Abidjan, in Lubumbashi)	[No response provided]

14 Stakeholders

STAKEHOLDER	DESCRIPTION OF ENGAGEMENT
Local Hospitals/Health Facilities	The program signed agreements with some local hospitals (Curie - IOTA, Curie- Gabriel Touré hospital, AMCC - hospital in Madagascar) to provide care to Retinoblastoma patients. Agreements with more local hospitals will be signed soon.

Local Context, Equity & Sustainability

15 Local health needs addressed by program

The prognosis of Retinoblastoma has been poor in developing countries due to late diagnosis, and treatment abandonment as a result of poor acceptance of enucleation as a lifesaving procedure [6-8] . This program seeks to improve the diagnosis and treatment of retinoblastoma and was made possible due to the existing collaboration of AMCC (French branch of International Network for Cancer Treatment and Research (INCTR)) and GFAOP (Franco-African Group of Pediatric Oncology), with pediatric oncologists and the creation of a specific unit for pediatric oncology in pediatric departments of university hospitals of these cities.

GFAOP has supported the oncology units for 5 tumors (Burkitt Lymphoma, Nephroblastoma, Acute Lymphoïd Leukemia, Hodgkin and Retinoblastoma) since 2002. The program has brought together pediatricians and ophthalmologists, who are major actors for early diagnosis and local treatment of patients with retinoblastoma. Bamako has a famous Institute of Tropical Ophthalmology and the teams have decided to work together within this project led by Professor Bey and the team from Curie Institute, referent center in France for retinoblastoma headed by Dr Laurence Desjardins, in order to demonstrate to the authorities that the treatment is efficient for a limited cost and can save lives and useful visions in most of the children. It is expected that Bamako will become a retinoblastoma training center for other African countries

16 Social inequity addressed

Yes. The program aims to allow all children with retinoblastoma to be treated. The medicines are provided by GFAOP (Franco-African Group of Pediatric Oncology), the prostheses are provided for free (charitable actions), and conservative treatment is done in public hospitals. The program pays part of the cost of treatment for the poorest families.

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

All aspects of our program including patients' examination and treatment are performed by trained and certified medical personnel and the treatments are consistent with local practices and guidelines. Trainings for pathologists and ophthalmologists were developed according to national guidelines.

18 How diversion of resources from other public health priorities are avoided

[No response provided]

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

[No response provided]

20 Health technologies are part of local standard treatment guidelines

N/A

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Local Context, Equity & Sustainability

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

The objective is to demonstrate to authorities (proof of concept) that children with early diagnosed retinoblastoma can be cured in more than 80% of cases with a cost of less than 1,500 US$ for one child and that it must be assumed by the ministry of health.

Additional Program Information

24 Additional program information

The program is quite similar in the different African countries where it is implemented. Some scientific publications related to this program are ongoing.

a Potential conflict of interest discussed with government entity

[No response provided]

25 Access Accelerated Initiative participant

Yes.

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

Yes.

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Resources

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2. Knudson AG. Mutation and cancer: statistical study of retinoblastoma. Proceedings of the National Academy of Sciences. 1971 Apr 1;68(4):820-3.

3. Lumbroso-Le Rouic L, Savignoni A, Levy-Gabriel C, Aerts I, Cassoux N, Salviat F, Gauthier-Villars M, Freneaux P, Brisse , Dendale R, Esteve M, Doz F, Desjardins L. Treatment of retinoblastoma: The Institut Curie experience on a series of 730 patients (1995 to 2009). J Fr Ophtalmol. 2015;38:535-41

4. Chantada G1, Schaiquevich P Management of retinoblastoma in children: current status. Paediatr Drugs. 2015;17:185-98

5. Chantada GL1Retinoblastoma: lessons and challenges from developing countries. Ellsworth Lecture 2011. Ophthalmic Genet. 2011;32:196-203

6. Ka AS, Imbert P, Moreira C, Niang A, Baujat G, Seye MN, Guyon P. Epidemiology and prognosis of childhood cancers in Dakar, Senegal. Medecine tropicale: revue du Corps de sante colonial. 2003;63(4-5):521-6.

7. Kazadi Lukusa A, Aloni MN, Kadima-Tshimanga B, Mvitu-Muaka M, Gini Ehungu JL, Ngiyulu R, Ekulu Mfutu P, Budiongo Nzazi A. Retinoblastoma in the democratic republic of congo: 20-year review from a tertiary hospital in kinshasa. Journal of Cancer Epidemiology. 2012 Apr 26;2012.

8. Boubacar T, Fatou S, Fousseyni T, Mariam S, Fatoumata DT, Toumani S, Abdoul-Aziz D, Marouf KM. A 30-month prospective study on the treatment of retinoblastoma in the Gabriel Toure Teaching Hospital, Bamako, Mali. British Journal of Ophthalmology. 2010 Apr 1;94(4):467-9

Program Indicators

PROGRAM ENDED IN 2018

PROGRAM NAME

My Child Matters- Retinoblastoma

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

	INDICATOR	TYPE	STRATEGY	2012	2015	2016	2017	2018
1	Value of resources	Input	All Program Strategies	---	---	---	---	51,000 euro
2	Patients with complete cancer remission	Outcome	Health Service Delivery	---	12 people	14 people	10 people	15 people
3	Health provider knowledge	Outcome	Health Service Strengthening	---	---	100 percent	100 percent	---
4	Number of people trained	Output	Health Service Strengthening	---	---	150 people	201 people	8 people
5	Time between first symptoms and diagnosis	Outcome	Health Service Delivery	---	---	---	---	60 days
6	Patients early diagnosed	Output	Health Service Strengthening	---	17 people	26 people	21 people	22 people
7	Number of diagnosed cases	Output	Health Service Strengthening	---	31 people	47 people	34 people	36 people
8	Number of ocular prosthesis	Output	Health Service Strengthening	---	13 people	17 people	18 people	22 people
9	Communication materials in use	Output	Community Awareness and Linkage to care	1002 tools	---	---	---	2 tools
10	Number of patients on treatment	Output	Health Service Delivery	---	---	---	35 people	36 people

INDICATOR **Value of resources**

STRATEGY ALL PROGRAM STRATEGIES

1

	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	Company	A member of the Sanofi Espoir Foundation team records the payment of the grant allocated for 3 years.	Every 3 years
31	Data processing	Company	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	DATA NOT AVAILABLE BY YEAR (2012-2015)	2017	2018
1 Value of resources	$246727.53	---	51,000 euros

Comments:

2012-2015: Data correspond to a funding of a 3 years cycle.

INDICATOR **Patients with complete cancer remission**

STRATEGY N/A

2

	ITEM	DESCRIPTION
	Definition	Number of surviving children diagnosed with retinoblastoma showing a complete remission.
	Method of measurement	Number of treated surviving children with complete remission in the Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophtalmology.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excel sheet follow-up data from children with retinoblastoma in the Bamako pilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the project coordinator, counts the number of children treated for retinoblastoma with a complete remission in one year.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

It is possible that some loss to follow up of the children diagnosed with retinoblastoma impacts the overall survival rate data.

INDICATOR	2015	2016	2017	2018
2 Patients with complete cancer remission	12 people	14 people	10 people	15 people

Comments: 2018 data: 12 unilateral intraocular and 3 bilateral intraocular retinoblastoma.

INDICATOR **Health provider knowledge**

STRATEGY HEALTH SERVICE STRENGTHENING

3

	ITEM	DESCRIPTION
	Definition	Percentage of providers that pass the assessment examining their skills or knowledge. The exam should be designed to assess the possession of the skills and knowledge to be able to comply with predefined standards.
	Method of measurement	The assessment of possession of skills and knowledge occurs through a written, oral, or observational assessment that all providers have to undergo. CALCULATION: $\frac{\text{Number of providers who pass the assessment}}{\text{Number of providers trained}}$ x100
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: Curie Institute (Paris, France); Implementing partner: Prothelem	The trainers, member of the implementing partner, observe the trainees during their session in Paris to assess the possession of skills and knowledge. The trainees write a report summarizing the knowledge acquired during the sessions. The trainers read the report and record the trainees who validated the training session.	One -time event
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer)	A member of the implementing partner (AMCC) calculates the percentage of trainees who acquired the knowledge and skills needed for retinoblastoma management in the past training session based on the records kept by the trainers.	
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
3 Health provider knowledge	100%	100%	---

Comments: N/A

INDICATOR **Number of people trained**

STRATEGY HEALTH SERVICE STRENGTHENING

4

	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	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: Curie Institute (Paris, France); Implementing partner: Prothelem.	The number of people trained is the number of professionals who travelled from Africa to attend the training session in Curie institute. The implementing partners (AMCC and Curie Institute) keep a record of the number of professionals they trained in Paris.	One-time event
31	Data processing	Implementing partner: Curie Institute (Paris, France); Implementing partner: AMCC (Alliance Mondiale Contre le Cancer).	The implementing partner counts the number of persons they trained in the past training sessions based on their records and report the number to Sanofi Espoir Foundation.	One-time event
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
4 Number of people trained	150 people	201 people	8 people

Comments: 2018: 1 ophtalmologist from Mali for conservative treatments during 4 weeks at Curie Institute (Paris) - 1 nurse anesthesiologist from Mali - 6 ophtalmologists : 3-day seminar on multidisciplinary care in Senegal.

INDICATOR **Time between first symptoms and diagnosis** 5

STRATEGY HEALTH SERVICE DELIVERY

	ITEM	DESCRIPTION
	Definition	Median time between first symptoms of the medical condition reported by the patients and the diagnosis by a trained health care professional.
	Method of measurement	The health facility patient medical recorders should provide the information on the time reported by the patients between the first symptoms and the clinical diagnosis. The measurement should be taken in a representative sample of the patients with the medical condition under study. CALCULATION: Median number of days between the first symptoms of the medical condition and its diagnosis by a trained health care professional for all patients with symptoms and then diagnosed.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excel sheet the medical history and clinical data of children diagnosed with retinoblastoma in the Bamako pilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the implementing partner, calculates the median number of days between the first symptoms of retinoblastoma reported by the patients' caregivers and the diagnosis.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

The main challenge is the difficulty for families to remember when the first symptoms appear. It could involve memorization bias.

INDICATOR		2017	2018
5	Time between first symptoms and diagnosis	---	60 days

Comments: 60 days between the first symptoms and the diagnosis.

INDICATOR **Patients early diagnosed**

STRATEGY HEALTH SERVICE STRENGTHENING

6

	ITEM	DESCRIPTION
	Definition	Proportion of children diagnosed with retinoblastoma at early stage.
	Method of measurement	Number of diagnosis at early stage over all retinoblastoma diagnosed in the Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophthalmology.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excelsheet follow-up data from children with retinoblastoma in the Bamako pilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the project coordinator, calculates the proportion of children diagnosed with retinoblastoma at early stage by dividing the number diagnosed at early stage by the total number of children diagnosed with retinoblastoma in one year.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2015	2016	2017	2018
6 Patients early diagnosed	17 people	26 people	21 people	22 people

Comments: 2018: 14 unilateral intraocular - 8 bilateral intraocular.

INDICATOR **Number of diagnosed cases**

STRATEGY HEALTH SERVICE STRENGTHENING

7

	ITEM	DESCRIPTION
	Definition	Number of children with retinoblastoma.
	Method of measurement	Counting of diagnosed children with retinoblastoma in one year in the Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophthalmology.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excelsheet the number of diagnosed children with retinoblastoma in the Bamakopilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the project coordinator, counts the number of children diagnosed with retinoblastoma in the past year from records at Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophthalmology.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2015	2016	2017	2018
7 Number of diagnosed cases	31 people	47 people	34 people	36 people

Comments: N/A

INDICATOR **Number of ocular prosthesis**

STRATEGY HEALTH SERVICE STRENGTHENING

8

	ITEM	DESCRIPTION
	Definition	Number of children having an ocular prosthesis after enucleation.
	Method of measurement	Counting of children with ocular prosthesis after enucleation in one year in the Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophthalmology.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excel sheet the number of ocular prosthesis implantation for children with retinoblastoma treated by enucleation in the Bamako pilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the implementing partner, counts the number of children that received ocular prosthesis after enucleation in one year in the Pediatric Oncology Unit at Gabriel Toure teaching Hospital and The Institute of African Tropical Ophthalmology.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2015	2016	2017	2018
8 Number of ocular prosthesis	13 people	17 people	18 people	22 people

Comments: 2018: All patients enucleated benefited from ocular prosthesis.

INDICATOR **Communication materials in use**

STRATEGY COMMUNITY AWARENESS AND LINKAGE TO CARE

9

	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.
28	Data source	Routine program data
29	Frequency of reporting	Once per year

		RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30	Data collection	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: Curie Institute (Paris, France); Healthcare team at local hospitals; Implementing partner: private funders: Retinostop association, Local associations or foundations (in Abidjan, in Lubumbashi); Implementing partner: Public Hospitals	The local teams created TV spots, posters and flyers to communicate about early symptoms of Retinoblastoma. The implementing partner (AMCC) helps in printing these tools and records the number of posters and flyers printed.	One-time event
31	Data processing	Implementing partner: Curie Institute (Paris, France); Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: Private funders: Retinostop association, Local associations or foundations (in Abidjan, in Lubumbashi); Implementing partner: Public Hospitals; Healthcare team at local hospitals	The implementing partner sums the number of posters and fliers printed on their records and report the number to Sanofi Espoir Foundation.	One-time event
32	Data validation		No implemented process.	

33 Challenges in data collection and steps to address challenges

The main challenge is that the implementing partners cannot provide data about the number of posters and fliers effectively distributed and displayed on the local unit.

INDICATOR		2012	2017	2018
9	Communication materials in use	1002 tools	---	2 tools

Comments: 2018: 1 TV spot for early diagnosis of retinoblastoma : 12 appearances on national TV. 1 TV report on Canal + Africa.

INDICATOR

Number of patients on treatment

10

STRATEGY HEALTH SERVICE DELIVERY

	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	Healthcare team at local hospitals	The doctor leading the Bamako pediatric oncology unit collects in an excel sheet the clinical data, exact diagnosis and protocol of treatment of children with retinoblastoma in the Bamako pilot and Abidjian (from 2017) units.	Ongoing
31	Data processing	Implementing partner: AMCC (Alliance Mondiale Contre le Cancer); Implementing partner: GFAOP (Groupe Franco-Africain d'Onco-Pédiatrie); Healthcare team at local hospitals	Once a year, the doctor leading the Bamako pediatric oncology unit, helped by the implementing partner, counts the number of children receiving treatment for retinoblastoma in the past one year.	Once per year
32	Data validation		The project coordinator (AMCC) visits the local team once a year to verify and review the data according to the protocol elaborated by Retinoblastoma committee of Franco-African Pediatric Oncology Group (GFAOP).	

33 Challenges in data collection and steps to address challenges

There is no challenge to report for this indicator.

INDICATOR	2017	2018
10 Number of Patients on Treatment	35 people	36 people

Comments: N/A

Program Documents

PROGRAM ENDED IN 2018

Program Documents

1. Traore, F., Togo, B., Sylla, F., et al. Le rétinoblastome : état des lieux au Mali et programme d'aide au diagnostic précoce, aux traitements et à la réhabilitation. Bull Cancer 2013; 100: 161-165. Available at: https://www.sciencedirect.com/science/article/abs/pii/S0007455115302733

2. Bey, P., Traore, F., Sylla, F., et al. Retinoblastoma: an exemplary tumour in young children that can be cured in low-income countries. Cancer Control 2014; 111-114. Available at: http://www.cancercontrol.info/wp-content/uploads/2014/08/111-114-BEY_cc2014.pdf

3. My Child Matters brochure. Sanofi Espoir Foundation, 2015. Available at: https://bit.ly/mychildmatters

2. The UICC My Child Matters inititative 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

3. Burton, A. UICC My Child Matters awards: 2006 winners. Lancet Oncol 2007; 8(2): 99. Available at: https://www.thelancet.com/journals/lanonc/article/PIIS1470204506709822/fulltext

4. Burton, A. 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

5. Masera, G. 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

6. 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

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 you 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 are 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

a. Responsible party: For this indicator, please indicate the party/parties responsible for data collection.

b. Data collection — Description: Please briefly describe the data source and collection procedure in detail.

c. Data collection — Frequency: For this indicator, please indicate the frequency of data collection.

31 Data processing

a. Responsible party: Please indicate all parties that conduct any processing of this data.

b. 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.

c. 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.

PROGRAM ENDED IN 2018

Company-submittes Situation Analysis

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