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# Global HOPE Africa

Bristol-Myers Squibb Foundation

Submitted as part of Access Accelerated

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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](http://www.accessobservatory.org)

The information contained in this report is in the public domain and should be cited as: Bristol-Myers Squibb, Global HOPE - Africa (2020), Access Observatory Boston, US 2020 (online) available from [www.accessobservatory.org](http://www.accessobservatory.org)

# Program Description

# Program Overview

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## 1 Program Name

Global HOPE (Africa)

## 2 Diseases program aims to address

- Cancer (Childhood)
- Other NCD (Blood Disorder)

## 3 Beneficiary population

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

## 4 Countries

- Botswana
- Malawi
- Uganda

## 5 Program start date

November 01, 2016

## 6 Anticipated program completion date

December 31, 2021

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## 8 Program summary

Global HOPE (Hematology-Oncology Pediatric Excellence) is a comprehensive initiative which aims to build long-term capacity to treat and dramatically improve the prognosis of thousands of children with cancer and blood disorders in southern and eastern Africa. The Bristol-Myers Squibb Foundation has committed \$50 million over five years to fund the training of healthcare providers as well as clinical infrastructure and operations. Texas Children's Hospital and the Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI) are contributing an additional \$50 million for the initiative.

Global HOPE is a partnership with local governments and Ministries of Health (MOH) to build medical capacity to diagnose and treat pediatric blood disorders and cancer in Botswana, Malawi and Uganda. The initiative aims to create significant clinical, educational and research capabilities. As part of the initiative, doctors, nurses and ancillary professionals are recruited from around the world to provide training to local healthcare professionals and to treat children with blood disorders and cancer. Botswana, Malawi and Uganda serve as regional hubs for pediatric hematology-oncology aspects of the initiative.

Primary program activities include:

- Treating more than 5,000 children with pediatric blood disorders and cancer in the first five years alone. During the first year, Global HOPE treated over 1,000 children with cancer and blood disorders. By operating within the national public healthcare system in each country, Global HOPE provides services at little to no cost to patients or their families, increasing access to PHO services for people of all income levels, especially low-income populations. Global HOPE also provides transportation assistance to patients and their families, many of whom live in rural areas and must travel long distances to receive care, decreasing financial barriers to accessing care for poor and/or rural populations.
- Constructing three regional Pediatric Hematology-Oncology (PHO) Centers of Excellence treatment and training sites, located in Botswana, Malawi and Uganda.

# Program Overview

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## 8 Program summary cont.

- Establishing two PHO Fellowship Programs (in Southern Africa and East Africa), to train doctors in specialized PHO care. Botswana will serve as the regional training hub for the Southern Africa PHO Fellowship and Uganda for East Africa.
- Training an estimated 4,700 healthcare providers (HCPs) from Botswana, Malawi, Uganda and other African countries in the first five years of the program. Trained HCPs will represent a variety of disciplines including physicians, nurses, social workers and other ancillary providers and administration staff along the cancer care continuum. Over 350 healthcare professionals were trained during the Global HOPE's first year. Global HOPE provides on-site training to local medical professionals, medical students and healthcare administration workers, working in partnership with the major medical schools in each country.
- Global HOPE also addresses the stigma and lack of awareness surrounding cancers and blood disorders through community awareness initiatives. Outreach activities will target healthcare workers (both professionals healthcare providers and community health workers) in district hospitals and rural health facilities, to help improve early and accurate diagnosis of cancer patients and referrals to PHO center for treatment. Community awareness activities will also target the general public, aiming to decrease stigma surrounding cancers and blood disorders and increase awareness of symptoms of childhood cancer and how to access PHO services.

<sup>1</sup> For more information on Global HOPE check: Creating Futures for Children with Cancer and Blood Disorders in Africa: <https://www.bms.com/assets/bms/us/en-us/pdf/global-hope-2017.pdf>

# Program Strategies & Activities

## 9 Strategies and activities

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

ACTIVITY	DESCRIPTION
Communication	Global HOPE addresses the stigma and lack of awareness surrounding pediatric hematology and oncology (PHO) through community awareness initiatives, to improve early and accurate diagnosis of cancer patients and referrals to PHO center for treatment
Planning	Global HOPE's Community Outreach and Awareness division is actively engaged in planning community awareness activities and developing educational tools and materials.
Infrastructure	Global HOPE is developing educational materials to inform and raise awareness of pediatric cancers and blood disorders.
Mobilization (e.g. support provided to mobilize communities)	Global HOPE will partner with and support local parent support groups and pediatric cancer survivors. Global HOPE has organized various Childhood Cancer Day and Cancer Survivor Day celebrations and activities.

### Strategy 2: Health Service Strengthening

ACTIVITY	DESCRIPTION
Planning	Engage with local governments and medical schools to develop training programs and build pediatric oncology capacity.
Training	Establish two PHO Fellowship Programs (in Southern Africa and East Africa), to train doctors in specialized PHO care. Provide onsite training to health care providers and students, including physicians, nurses, social workers and other ancillary providers.
Infrastructure	Construct three regional Pediatric Hematology-Oncology (PHO) Centers of Excellence treatment and training sites, located in Botswana, Malawi and Uganda.
Technology	Install medical technology, such as flow cytometers, in Global HOPE sites and train laboratory staff in the use of flow cytometry for cancer diagnosis.
Management	One of Global HOPE's capacity building activities is to train local leaders in PHO program management, including Medical Directors, PHO fellows, and PHO administrative leaders.

# Program Strategies & Activities

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## Strategy 3: Health Service Delivery

ACTIVITY	DESCRIPTION
Diagnosis	Diagnosis of children with pediatric blood disorders and cancer.
Treatment	Treatment of children with pediatric blood disorders and cancer.
Retention	Transportation assistance to PHO patients, many of whom must travel long distances to receive care. Contact patients and families to send reminders for scheduled visits, and follow-up after any missed visits.

### 10 Strategy by country

STRATEGY	COUNTRY
Community Awareness and Linkage to Care	Botswana, Malawi, Uganda
Health Service Strengthening	Botswana, Malawi, Uganda
Health Service Delivery	Botswana, Malawi, Uganda

# Companies, Partners & Stakeholders

## 11 Company roles

COMPANY	ROLE
Bristol-Myers Squibb	Co-Sponsor and co-funder. Bristol Myers Squibb (BMS), via the Bristol Myers Squibb Foundation (BMSF), has committed \$50 million in funding over the next five years to create an innovative pediatric hematology-oncology treatment network that aims to build long-term capacity to treat and dramatically improve the prognosis of thousands of children with blood disorders and cancer in southern and east Africa. BMS and its implementing partners are working with the governments of Botswana, Malawi and Uganda to develop the comprehensive treatment network and provide financial and in-kind resources to the program.

## 12 Funding and implementing partners

PARTNER	ROLE/URL	SECTOR
Botswana Ministry of Health	Government partner in the development of the pediatric oncology network and the regional Pediatric Hematology-Oncology (PHO) Center of Excellence treatment and training site in Botswana. <a href="http://www.moh.gov.bw/">http://www.moh.gov.bw/</a>	Public
Bristol-Myers Squibb Foundation	Co-sponsor and co-funder. BMSF is Bristol Myers Squibb's CSR Foundation, which BMS uses as a mechanism to fund public/global health initiatives. <a href="https://www.bms.com/about-us/responsibility/bristol-myers-squibb-foundation.html">https://www.bms.com/about-us/responsibility/bristol-myers-squibb-foundation.html</a>	Private
Malawi Ministry of Health	Government partner in the development of the pediatric oncology network and the regional Pediatric Hematology-Oncology (PHO) Center of Excellence treatment and training site in Malawi. <a href="http://www.health.gov.mw/">http://www.health.gov.mw/</a>	Public
Texas Childrens Cancer and Hematology Centers	Texas Children's Cancer and Hematology Centers (TXCH), as part of Texas Children's Hospital, is the primary implementing and managing partner. TXCH oversees Global HOPE program operations, treats PHO patients and trains healthcare professionals in Botswana, Malawi and Uganda. TXCH will oversee the construction of the three PHO Centers of Excellence, and has committed to contribute an additional \$50 million to the initiative. <a href="http://txch.org/">http://txch.org/</a>	Voluntary
Uganda Ministry of Health	Government partner in the development of the pediatric oncology network and the regional Pediatric Hematology-Oncology (PHO) Center of Excellence treatment and training site in Uganda. <a href="http://health.go.ug/">http://health.go.ug/</a>	Public



Baylor International Pediatric Aids Initiative (BIPAI)	Implementing partner, in collaboration with the BIPAI-affiliated local NGO in each country. Provides legal infrastructure for Global HOPE activities in-country, facilitates connections and partnerships with local government institutions, key stakeholders and other organizations in each country, supports fundraising, and provides core administrative support for program operations. <a href="http://bipai.org/">http://bipai.org/</a>	Voluntary
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### 13 Funding and implementing partners by country

PARTNER	COUNTRY
Bristol-Myers Squibb Foundation	Botswana, Malawi, Uganda
Botswana Ministry of Health	Botswana
Malawi Ministry of Health	Malawi
Uganda Ministry of Health	Uganda
Texas Childrens Cancer and Hematology Centers	Botswana, Malawi, Uganda
Baylor International Pediatric Aids Initiative (BIPAI)	Botswana, Malawi, Uganda

### 14 Stakeholders

STAKEHOLDER	DESCRIPTION OF ENGAGEMENT
Government	Partner with local Ministry of Health in Botswana, Malawi and Uganda through Memoranda of Agreement.
Local Hospitals / Health Facilities	Partner to treat more than 5,000 children with pediatric blood disorders and cancer in the first five years alone. Local hospital partners include: Mulago National Referral Hospital (Uganda), the Uganda Cancer Institute (Uganda), Kamuzu Central Hospital, Princess Marina Hospital (Botswana).
Local Universities	Partner in providing on-site training to local medical professionals and medical students. Local partners include: Makerere University College of Health Sciences (Uganda), the University of Botswana, and the Malawi College of Health Sciences.
Non-government organization (NGO)	Local BIPAI-affiliated NGOs: Botswana-Baylor Children's Centre of Excellence Trust, Baylor College of Medicine Children's Foundation-Malawi, Baylor College of Medicine Children's Foundation Uganda.

# Local Context, Equity & Sustainability

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## 15 Local health needs addressed by program

In the United States, 80 percent of children with cancer survive. In sub-Saharan Africa, the overwhelming majority of pediatric patients do not survive. The mortality rate is estimated to be as high as 90 percent, meaning that thousands of children die from cancer across Africa each year. While global public attention has been largely and understandably focused on HIV/AIDS, malaria and tuberculosis, cancer kills more people in low- and middle-income countries than all of these terrible diseases combined. This is in large part due to an inadequate healthcare infrastructure and a significant lack of expert physicians and other healthcare workers trained to treat children with cancer. The most common types of childhood cancers are blood cancers, including leukemia and lymphoma.

There are only six pediatric oncologists currently in the countries of Botswana, Malawi and Uganda combined, five of whom are members of Global HOPE. There are simply not enough expert doctors to treat all the children diagnosed with blood disorders and cancer. It is estimated that in these countries there are more than 11,000 new cases annually of pediatric cancer and 40,000 new cases of serious, life-threatening blood disorders such as sickle cell disease and hemophilia. Because of these staggering numbers, more healthcare providers with special expertise are urgently needed.

Global HOPE was invited by the Ministries of Health (MOH) in Botswana, Malawi and Uganda to help address pediatric hematology oncology (PHO) needs; these partnerships with each MOH were formalized with the signing of Memoranda of Agreement (MOA) with the MOH in each country. Global HOPE (Hematology-Oncology Pediatric Excellence) aims to directly and effectively address the significant unmet healthcare needs for childhood cancer in eastern and southern Africa by building developing and operating an innovative pediatric hematology-oncology (PHO) treatment network to provide build long-term capacity to treat and dramatically improve the prognosis of thousands of children. To make this happen, the Bristol Myers Squibb Foundation, Texas Children's Hospital (TCH) and Baylor College of Medicine International Pediatric AIDS Initiative at Texas Children's Hospital (BIPAI) have committed a combined \$100 million. This commitment supports the training network and the construction, equipping and operation of three regional pediatric hematology-oncology clinical sites in Botswana, Malawi and Uganda.

### a How needs were assessed

[No response provided]

### b Formal needs assessment conducted

[No response provided]

## 16 Social inequity addressed

In the United States, 80 percent of children with cancer survive. This is in stark contrast to sub-Saharan Africa, where up to 90% of pediatric cancer patients die. This disparity is in large part due to an inadequate healthcare infrastructure and a significant lack of expert physicians and other healthcare workers trained to treat children with cancer.

Global HOPE aims to increase access to and improve the quality of pediatric hematology and oncology (PHO) care in Sub-Saharan Africa, thus decreasing the disparity in PHO survival between SSA and the United States. Global HOPE aims to address this inequity by building PHO capacity in the healthcare systems in Botswana, Malawi, Uganda, and other countries in the region. With only six pediatric oncologists currently in the countries of Botswana, Malawi and Uganda combined, there are not enough expert doctors to treat all the children diagnosed with blood disorders and cancer. By supporting the development of local PHO leaders and training HCPs in PHO care, Global HOPE is strengthening local capacity to diagnose and treat children with cancers and blood disorders.

Cost is often a barrier to accessing PHO care; in many low-income countries, private health facilities may be the only option to receive care/treatment for pediatric cancers. By operating within national health system in each country, Global HOPE is strengthening the

# Local Context, Equity & Sustainability

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## 16 Social inequity addressed, cont.

quality of care in public healthcare facilities, providing quality PHO services at little or no cost to patients and their families. Global HOPE also provides transportation assistance, offsetting travel costs that can place a financial strain on families of PHO patients and/or deter families from seeking treating, many of whom must travel long distances to receive care.

The construction of the Global HOPE Centers of Excellence will also contribute to decreasing the inequity in access to PHO services. These state-of-the-art facilities will be specifically designed to provide quality PHO care, and will be outfitted with high quality cancer diagnostic and laboratory equipment and treatment facilities.

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

Global HOPE's mission to provide care and treatment for children with cancer and blood disorders are aligned with the Ministry of Health's national strategic plans in each of our partner countries, and are specifically linked with national strategic objectives addressing child mortality and non-communicable diseases (specifically cancers and blood disorders). Global HOPE's objectives are also aligned with the UN Sustainable Development Goals, specifically the goals to reduce mortality in newborns and children under five, reduce mortality from non-communicable diseases, and providing access to quality essential health care services. Global HOPE was approached by the Ministries of Health (MOH) in Botswana, Malawi, and Uganda, to support PHO care in their respective countries. Global HOPE has partnered with local governments and the MOH in each country, through signed Memoranda of Agreement (MOA), to build medical capacity to diagnose and treat pediatric blood disorders and cancer. As public-private partnerships, the various governments will each play an important role in developing the pediatric hematology-oncology network, assisting with the training, technical assistance, logistics and resources to support Global HOPE. Global HOPE operates through the local BIPAI NGOs in each country; these NGOs have a long, established relationship with BMSF and the local governments in each country, and operate according to local laws and regulations, allowing Global HOPE to leverage existing experience, infrastructure, and public/private partnerships created through the initiative.

## 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 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.

# Local Context, Equity & Sustainability

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## 23 Sustainability plan

Global HOPE has engaged a number of local partners, including local government entities, hospitals, educational institutions and other local organizations; this engagement included the signing Memoranda of Agreement (MOA) with the Ministries of Health in Botswana, Malawi and Uganda. As part of the MOAs, Ministries of Health are supporting the development of the Pediatric Hematology-Oncology (PHO) Centers of Excellence (COEs), which will treat patients and train professionals after the funding period has ended. To help sustain the COEs, we are establishing local PHO advisory boards, which will review progress toward sustainability at regular intervals. Global HOPE has established the first ever PHO Fellowship in East Africa in Kampala, Uganda, and plans to establish another regional PHO Fellowship for Southern Africa in Botswana. This accredited two-year fellowship accepts a new class of 4 fellows each year, and trains physicians from around the East Africa region in the PHO specialty; in addition to medical training, fellows receive training in PHO program management and leadership. As part of our Memorandum of Agreement, the Ministry of Health of Uganda has agreed to hire the PHO Fellowship Program graduates, providing job security and an incentive for PHO Fellows to continue to practice in Uganda in the public sector, helping to prevent brain drain. The PHO Fellowship Program curriculum is currently undergoing the accreditation process with the Uganda Medical and Dental Practitioners Council. Once the process is completed, the PHO Fellowship in Uganda will be a nationally certified and recognized PHO training program.

As part of its capacity building activities, Global HOPE is utilizing a train-the-trainer model to train local healthcare workers through each country and subsequently transfer PHO expertise and knowledge to the local health workforce at all levels of the national healthcare system. In addition to training clinical healthcare professionals, Global HOPE is training local leaders in PHO program operations and administration: Global HOPE is hiring and training local program managers, financial analysts, Monitoring and Evaluation (M&E) officers, education and research coordinators, and other administrative staff in each of our sites (Botswana, Malawi and Uganda), to create truly locally led PHO Centers of Excellence that have the capacity to manage PHO program operations. Finally, Global HOPE has initiated active fundraising campaigns, with local governments committing funds, including \$6 million from Botswana.

# Additional Program Information

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24 Additional program information

[No response provided]

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.

# Resources

1. Creating Futures for Children with Cancer and Blood Disorders in Africa: <https://www.bms.com/assets/bms/us/en-us/pdf/global-hope-2017.pdf>

# Program Indicators

## PROGRAM NAME

# Global HOPE (Africa)

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

INDICATOR	TYPE	STRATEGY	2017	2018	2019
1 Number of people trained	Output	Health Service Strengthening	369 people	---	---
2 Number of patients initiating treatment	Outcome	Health Service Delivery	558 people	---	---
3 Number of patients formally diagnosed	Output	Health Service Delivery	673 people	---	---
4 Number of patients retained in care	Output	Health Service Delivery	439 people	---	---



INDICATOR **Number of people trained**

STRATEGY HEALTH SERVICE STRENGTHENING

1

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

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: Texas Childrens Cancer and Hematology Centers	Training facilitators ask training participants to sign an attendance form at each training. Fellows track their training activities and report to local M&E Officer on a monthly basis. Trainings occur on an ongoing basis (lectures, mock-exams, clinical rotations, etc.).	Ongoing
31 Data processing	Implementing partner: Texas Childrens Cancer and Hematology Centers	Attendance forms and training records are given to Monitoring & Evaluation (M&E) and Data Entry staff, who enter data into the relevant database. Entries are reviewed by M&E staff for data quality, to identify duplicates, errors and missing data, and take appropriate steps to correct them.	Ongoing
32 Data validation		Local M&E staff at each site will conduct routine quality control measures. M&E staff from Texas Children's Cancer and Hematology Centers will also visit each site once per year to conduct data quality assessments and verify data collection and management procedures.	

33 Challenges in data collection and steps to address challenges

Delays in hiring data entry staff have slowed data collection, we are currently in the process of hiring and onboarding data clerks at Global HOPE sites; internet connectivity issues slow data collection, we are currently troubleshooting and working to improve the internet connection at each site.

INDICATOR	2017	2018	2019
1 Number of people trained	369 people		---

Comments: Number of healthcare workers trained in reporting period: 10/01/2016 - 11/30/2017.

ITEM	DESCRIPTION
Definition	The number of patients with a pediatric cancer of blood disorder diagnosis (PHO) initiating treatment during the reporting period
Method of measurement	Count of patients with a PHO diagnosis who have initiated treatment
28 Data source	External non-public data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: Texas Childrens Cancer and Hematology Centers	Medical staff routinely update medical records on an ongoing basis. Medical staff abstract relevant medical data, including treatment info, which is then given to data entry staff, who enter data into database.	Ongoing
31 Data processing	Implementing partner: Texas Childrens Cancer and Hematology Centers	Local medical staff review and update medical records, including diagnosis info, on an ongoing basis. Monitoring & Evaluation (M&E) staff review and process clinical data, including diagnosis information, on a monthly basis. Processing steps include: reviewing for completeness and accuracy, following-up with medical staff, recoding or cleaning variables, combining data sources as needed.	Every month
32 Data validation		Local M&E staff at each site will conduct routine quality control measures. M&E staff from Texas Children’s Cancer and Hematology Centers will also visit each site once per year to conduct data quality assessments and verify data collection and management procedures.	

33 Challenges in data collection and steps to address challenges

Delays in hiring data entry staff have slowed data collection, we are currently in the process of hiring and onboarding data clerks at Global HOPE sites; internet connectivity issues slow data collection, we are currently troubleshooting and working to improve the internet connection at each site; health facilities utilize paper medical records, requiring more time to abstract clinically relevant data (files can be disorganized, handwriting can be illegible, combining data from multiple sources, etc.), the addition of data entry staff will alleviate this burden and we are currently exploring electronic medical records (EMR) and other records management solutions.

INDICATOR	2017	2018	2019
2 Population exposed to community communication activities	558 people	---	---

Comments: N/A

INDICATOR **Number of patients formally diagnosed**

STRATEGY HEALTH SERVICE DELIVERY

3

ITEM	DESCRIPTION
Definition	Number of patients formally diagnosed with a target disease (pediatric cancers and blood disorders). Formal diagnosis includes: histopathology, flow cytometry, autopsy, radiology/imaging, immunohistochemistry, molecular diagnosis. Diagnosis based on clinical findings alone is not sufficient
Method of measurement	Count of patients with a cancer diagnosis confirmed with at least one mode of formal diagnosis
28 Data source	External non-public data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: Texas Childrens Cancer and Hematology Centers	Clinicians routinely update patient medical records, including mode of diagnosis. Medical staff abstract relevant medical data, including treatment info, which is then given to data entry staff, who enter data into database.	Ongoing
31 Data processing	Implementing partner: Texas Childrens Cancer and Hematology Centers	Local medical staff review and update medical records, including diagnosis info, on an ongoing basis. Monitoring & Evaluation (M&E) staff review and process clinical data, including diagnosis information, on a monthly basis. Processing steps include: reviewing for completeness and accuracy, following-up with medical staff, recoding or cleaning variables, combining data sources as needed.	Every month
32 Data validation		Local M&E staff at each site will conduct routine quality control measures. M&E staff from Texas Children’s Cancer and Hematology Centers will also visit each site once per year to conduct data quality assessments and verify data collection and management procedures.	

33 Challenges in data collection and steps to address challenges

Delays in hiring data entry staff have slowed data collection, we are currently in the process of hiring and onboarding data clerks at Global HOPE sites; internet connectivity issues slow data collection, we are currently troubleshooting and working to improve the internet connection at each site; health facilities utilize paper medical records, requiring more time to abstract clinically relevant data (files can be disorganized, handwriting can be illegible, combining data from multiple sources, etc.), the addition of data entry staff will alleviate this burden and we are currently exploring electronic medical records (EMR) and other records management solutions.

INDICATOR	2017	2018	2019
3 Number of patients formally diagnosed	673	---	---

Comments: Number of pediatric cancer patients formally diagnosed in the reporting period. Note: this figure currently only represents pediatric cancer patients, it does not include patients with pediatric blood disorders (this will be reported at a later date).

ITEM	DESCRIPTION
Definition	The number of PHO patients who have initiated treatment who are retained in care
Method of measurement	Count of patients who have initiated treatment who are currently retained in care. Exclusion criteria: patients who have died, abandoned therapy, or lost-to-follow-up
28 Data source	External non-public data
29 Frequency of reporting	Once per year

	RESPONSIBLE PARTY	DESCRIPTION	FREQUENCY
30 Data collection	Implementing partner: Texas Childrens Cancer and Hematology Centers	Local medical staff routinely review and update medical records, including visit & patient outcome info, on an ongoing basis. Medical staff abstract relevant medical data, including retention info, which is then given to data entry staff, who enter data into database. Exclusion criteria: patients who have died, abandoned therapy, or lost-to-follow-up	Every month
31 Data processing	Implementing partner: Texas Childrens Cancer and Hematology Centers	Local medical staff review and update medical records, including visit & patient outcome (vital status, LTFU, etc.) info, on an ongoing basis. Monitoring & Evaluation (M&E) staff review and process clinical data, including visit and patient outcome information, on a monthly basis. Processing steps include: reviewing for completeness and accuracy, following-up with medical staff, recoding or cleaning variables, combining data sources as needed.	Every month
32 Data validation		Local M&E staff at each site will conduct routine quality control measures. M&E staff from Texas Children's Cancer and Hematology Centers will also visit each site once per year to conduct data quality assessments and verify data collection and management procedures.	

33 Challenges in data collection and steps to address challenges

Delays in hiring data entry staff have slowed data collection, we are currently in the process of hiring and onboarding data clerks at Global HOPE sites; internet connectivity issues slow data collection, we are currently troubleshooting and working to improve the internet connection at each site; health facilities utilize paper medical records, requiring more time to abstract clinically relevant data (files can be disorganized, handwriting can be illegible, combining data from multiple sources, etc.), the addition of data entry staff will alleviate this burden and we are currently exploring electronic medical records (EMR) and other records management solutions.

INDICATOR	2017	2018	2019
4 Number of patients retained in care	439 people	---	---

Comments: N/A

# 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 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

- 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.

