American Cancer Society®

Importance of Navigating Patients in Health Systems, Clinics, and Communities

ICCP ECHO April 2023 session

Kristie McComb, Managing Director
Global Capacity Development & Patient Support

Wednesday, April 19, 2023

Survivors/volunteers of **Cancer Awareness and Information Center (CISC)** Indonesia, a BEACON Initiative pilot organization, at one of two patient care homes they operate in Jakarta.

Organizational Commitment to Health Equity

We believe all people should have a fair and just opportunity to live a longer, healthier life free from cancer regardless of how much money they make, the color of their skin, their sexual orientation, gender identity, disability status, or where they live.

This means that our work extends beyond our borders through:

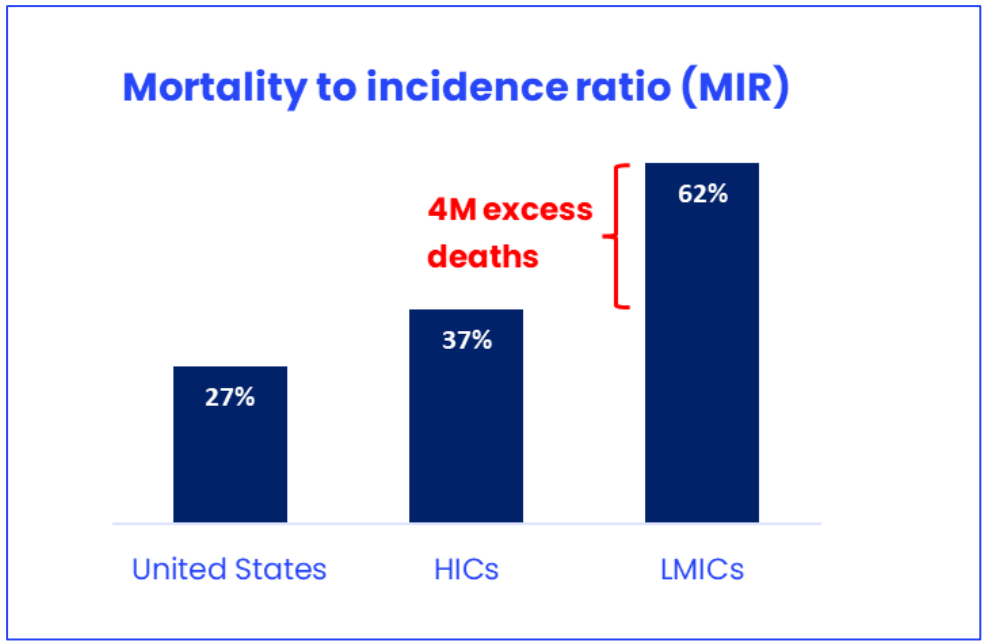
- **convening stakeholders**
- **fostering partnerships and**
- **building capacity.**

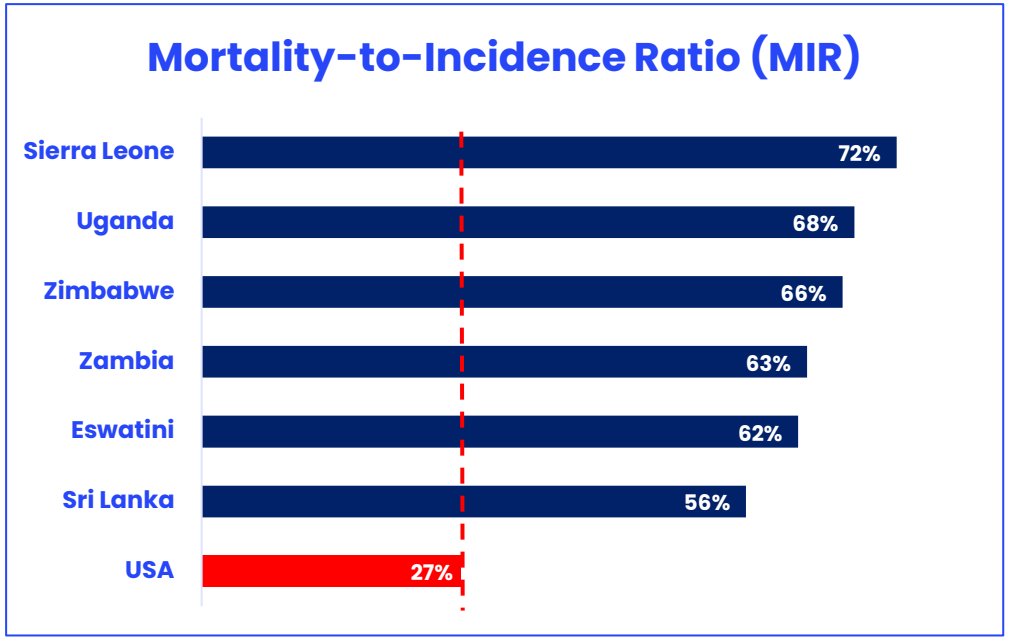
A cancer patient staying at a partner's patient care home in Kampala, Uganda while undergoing several months of treatment.

Learn about ACS' commitment to advancing health equity and addressing cancer disparities.

Geography of Global Cancer Disparities

- **Incidence: 59% of new cancer cases each year occur in low-and middle-income countries (LMICs)—11.4 million**—and incidence is predicted to double in the next 20 years.
- **Mortality: 71% of the world's cancer-related deaths occur in LMICs.** As a result, cancer causes **4 million more deaths** each year in LMICs compared to HICs.





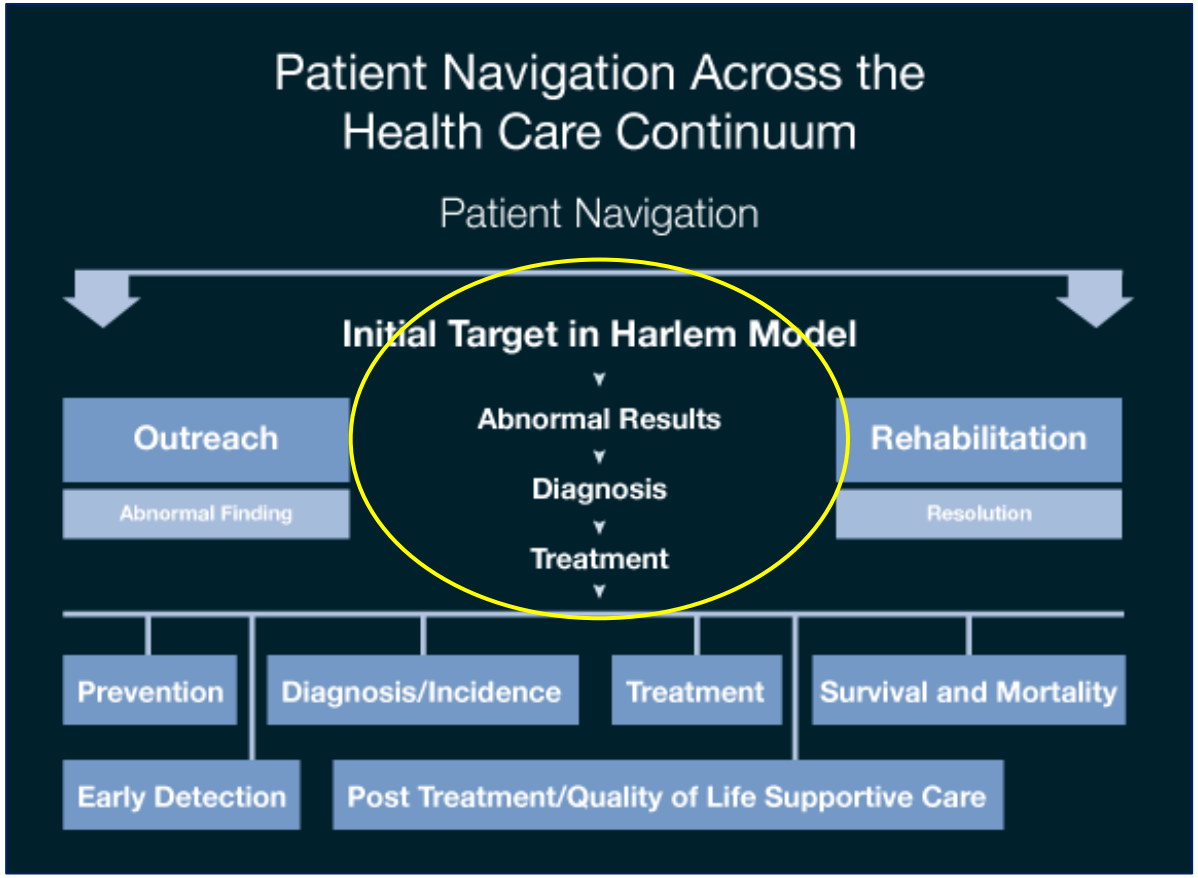
What is Patient Navigation?

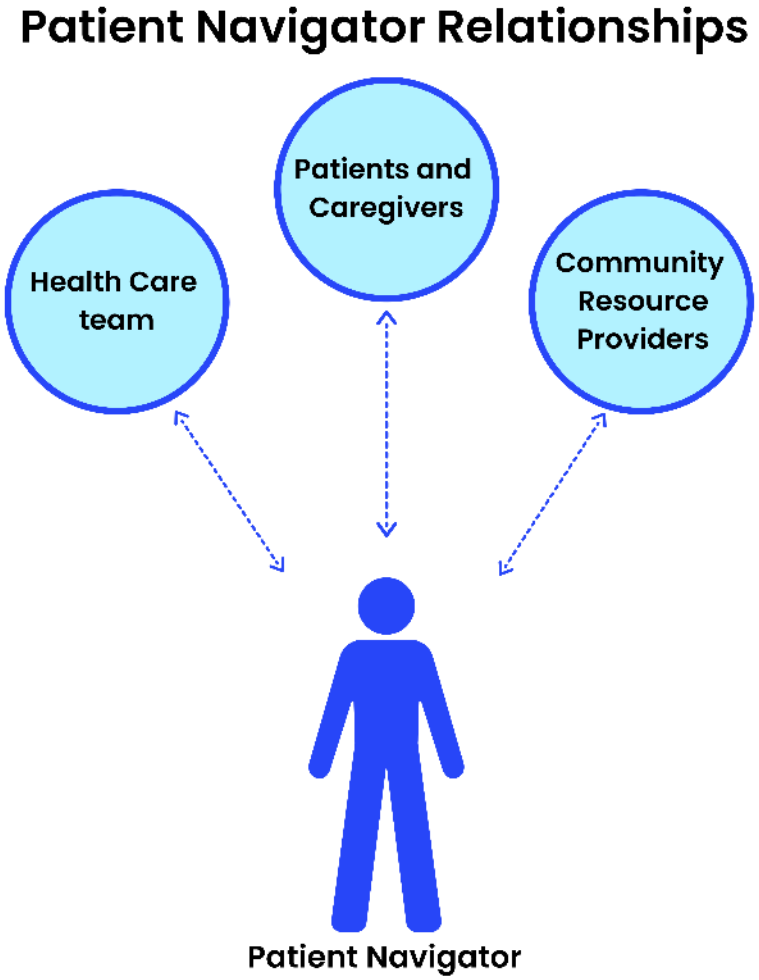
In the cancer care setting, Patient Navigation refers to **individualized assistance offered to patients, families, and caregivers** to help **overcome health care system barriers** and facilitate **timely access to quality health and psychosocial care** from pre-diagnosis through **all phases of the cancer experience.**

GOALS

- Eliminate barriers to care
- Ensure timely delivery of services
- ***Save lives from cancer***

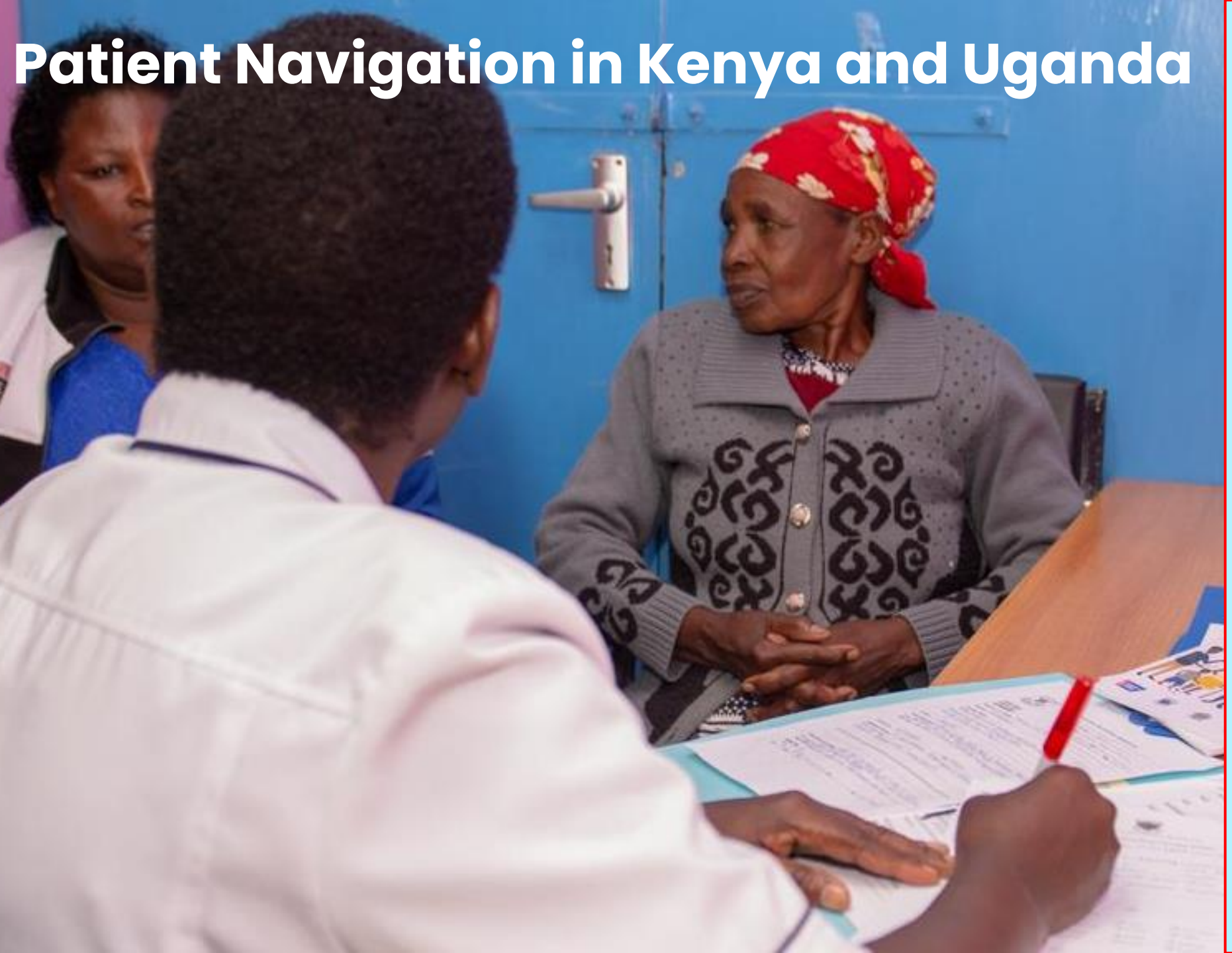
Goals and Phases of Patient Navigation





The field of patient navigation started in the diagnosis/treatment phase, but we now know it has applicability across the entire cancer care continuum.

Patient Navigation in Kenya and Uganda



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KENYA

Kenyatta National Hospital (2017-present)

11,680 patients navigated since 2017

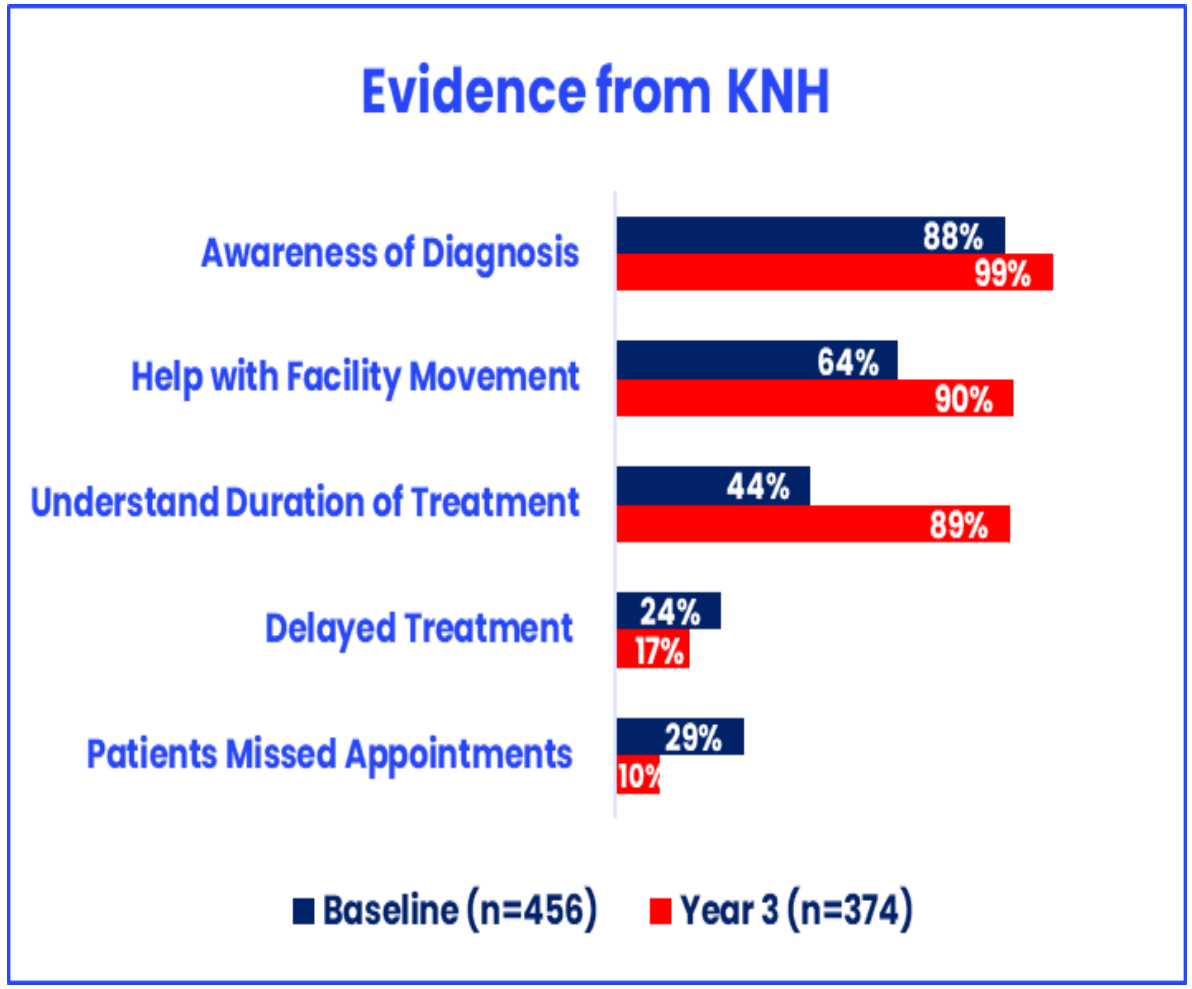
UGANDA

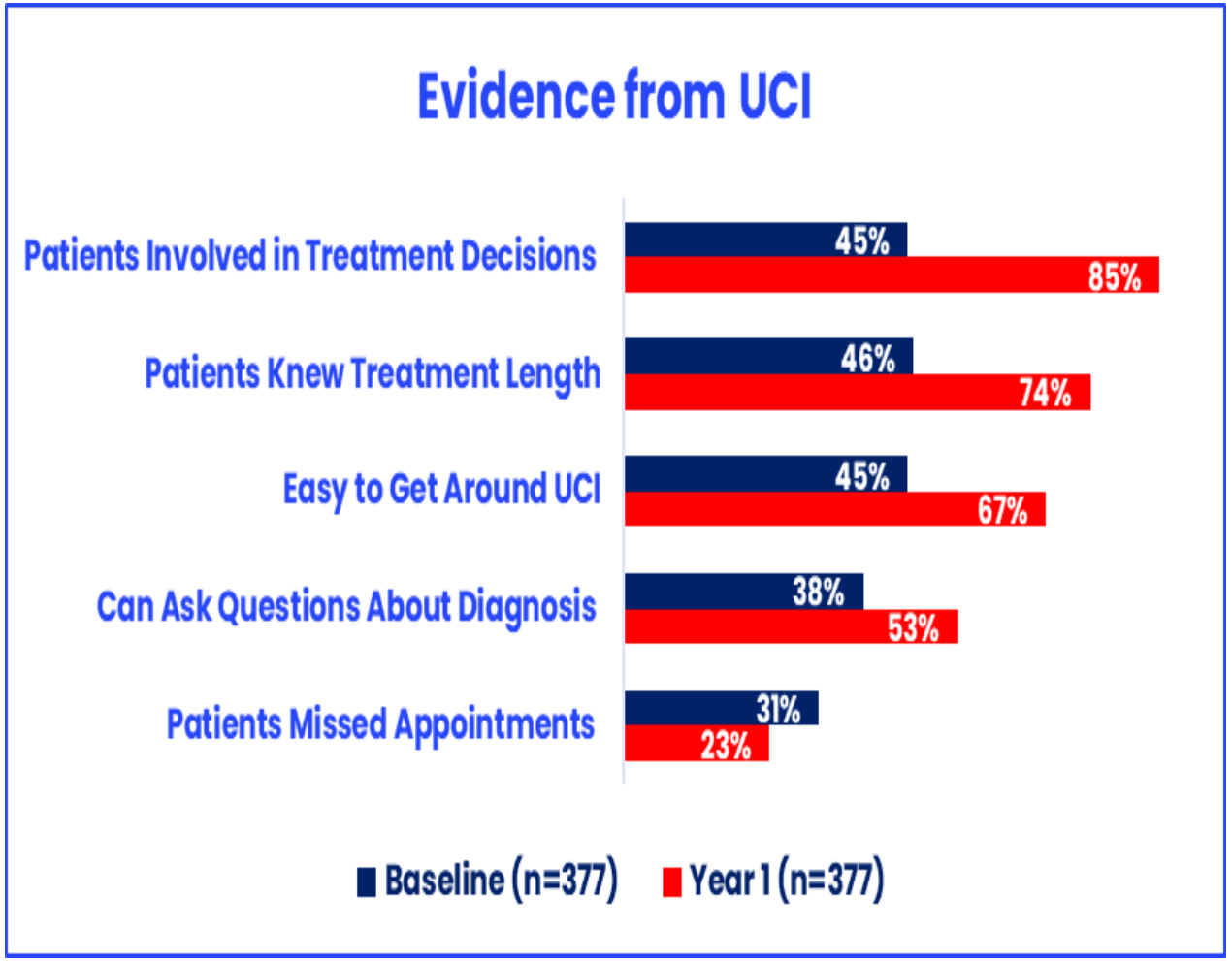
Uganda Cancer Institute (2021-present)

3720 patients navigated since 2021

To date, the two programs have navigated 15,400 patients!

Effectiveness of Patient Navigation in LMICs





Outcome Evaluation of the KNH Program

"The patient navigation program has shown that if the patients are involved and supported with information around their cancer treatment journey and are allowed to ask questions at any given time, the treatment journey becomes easier for them. Before the program, patients' treatment was very transactional, and the doctors and patients were very hostile to one another."

"It is indispensable for effective cancer care. It fits in the Kenyan set up and the developing countries very well that it should be required in the developed countries. In Kenya for instance, we have a lot of basic challenges like patients not being able to ask their way around or understand complex terminologies used in cancer treatment. In Kenya, it's very crucial as people prefer verbal communication and feedback supported by the patient's navigation program. Many patients appreciate the program. It really does fit within the Kenyan Cancer priorities."

Learn more about the KNH Patient Navigation Program.

The ACS BEACON Initiative

The **ACS BEACON *(Building Expertise, Advocacy, and Capacity for Oncology Navigation)* Initiative** supports health systems in LMICs to design, implement, and sustain oncology patient navigation programs.

Global Patient Navigation Toolkit

Peer Learning Collaborative

Digital Platform

Monitoring, Evaluation and Learning

ACS will complete a 15-month pilot of the BEACON Initiative this month with a full public launch in 2024.

Learn more about the BEACON Initiative.

BEACON Toolkit Design

How is the Toolkit unique and responsive?

Bridges the Global Gap

Recognizes Users as the Experts

Prepares Users to:

- **Cultivate** a team approach
- **Measure** outcomes of interest and share progress
- **Anticipate** and **manage** change
- **Plan for** and **achieve** sustainability

Is Flexible, Holistic, and Dynamic

Facilitates Adaptation to Local Context

Learn more about the BEACON Toolkit and Digital Platform.

Global Patient Navigation Toolkit

American Cancer Society

Table of Contents

GETTING STARTED
Learn How to Navigate the Toolkit

TOOLKIT TABLE OF CONTENTS
See What the Toolkit Includes

RESOURCE LIBRARY: COMING SOON
Find Toolkit Resources All in One Place

Phase 1: Lay the Foundation

SECTION 1
Learn Fundamentals of Patient Navigation

SECTION 2
Identify Service Delivery Gaps & Barriers to Care

SECTION 3
Create Your Vision & Mobilize Your Team

Phase 2: Design & Launch Your Program

SECTION 4
Determine Program Design & Key Activities

SECTION 5
Create Standards & Procedures

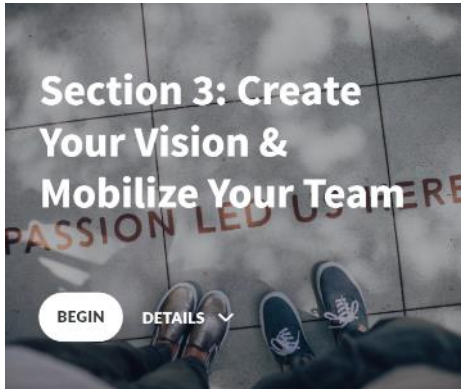
SECTION 6
Prepare Staff & Facility for Launch

Phase 3: Implement & Strengthen Your Program

SECTION 7
Learn From & Adapt Your Program

SECTION 8
Mobilize & Sustain Your Resources

SECTION 9
Support & Strengthen Your Team



Section 3 Overview

Build Your Base of Support (3.A)

Develop Partnerships for Patient Navigation (3.B)

Assemble your Design Team (3.C)

Create a Vision and Goals for your Patient Navigation Program (3.D)

Promote Patient Navigation (3.E)

Patient Navigation Stakeholders and their Potential Contributions

Stakeholder	Description Examples	Potential Contributions		
		Design and Pre-Implementation	Implementation	Sustainability
Internal – within your health care facility				
Health Care Facility Leadership & Management	Senior staff who oversee service delivery and control budgets. ○ CEO ○ Board of Directors ○ Administrators ○ Department Heads	• Approve ○ Program vision, goals, and objectives ○ Staffing and Budget ○ Standard Operating Procedures (SOPs) ○ Data collection forms and job aids • Endorse patient navigation	• Approve ○ Program Launch (if formal launch event) ○ Program promotional materials • Endorse patient navigation services • Help problem solve • Highlight and share program results	• Approve budgets and resource allocation to continue patient navigation activities • Endorse patient navigation integration • Help problem solve • Highlight and share program results
Health Care Facility Staff	Clinical and non-clinical staff in the health care facility - includes service providers and administrative staff. ○ Doctors and Nurses ○ Social workers ○ Human Resources ○ Patient Records ○ Quality Assurance ○ Facilities Management ○ Safety and Security	• Join Design Team • Become navigation Champions • Participate in cancer care inventory, patient flow, and needs assessments • Develop, review job descriptions • Support navigator recruitment and training • Develop program budget • Develop SOPs • Develop data collection forms and job aids	• Become or support program staff • Receive internal patient referrals • Create, review, use, patient education materials • Secure space and equipment • Support program launch • Address implementation challenges	• Provide feedback on patient navigation processes • Contribute to program Quality Assurance and/or Quality Improvement (QA/QI) • Interpret program data • Review and refine SOPs, forms, job aids, and patient materials

BEACON Peer Learning Collaborative

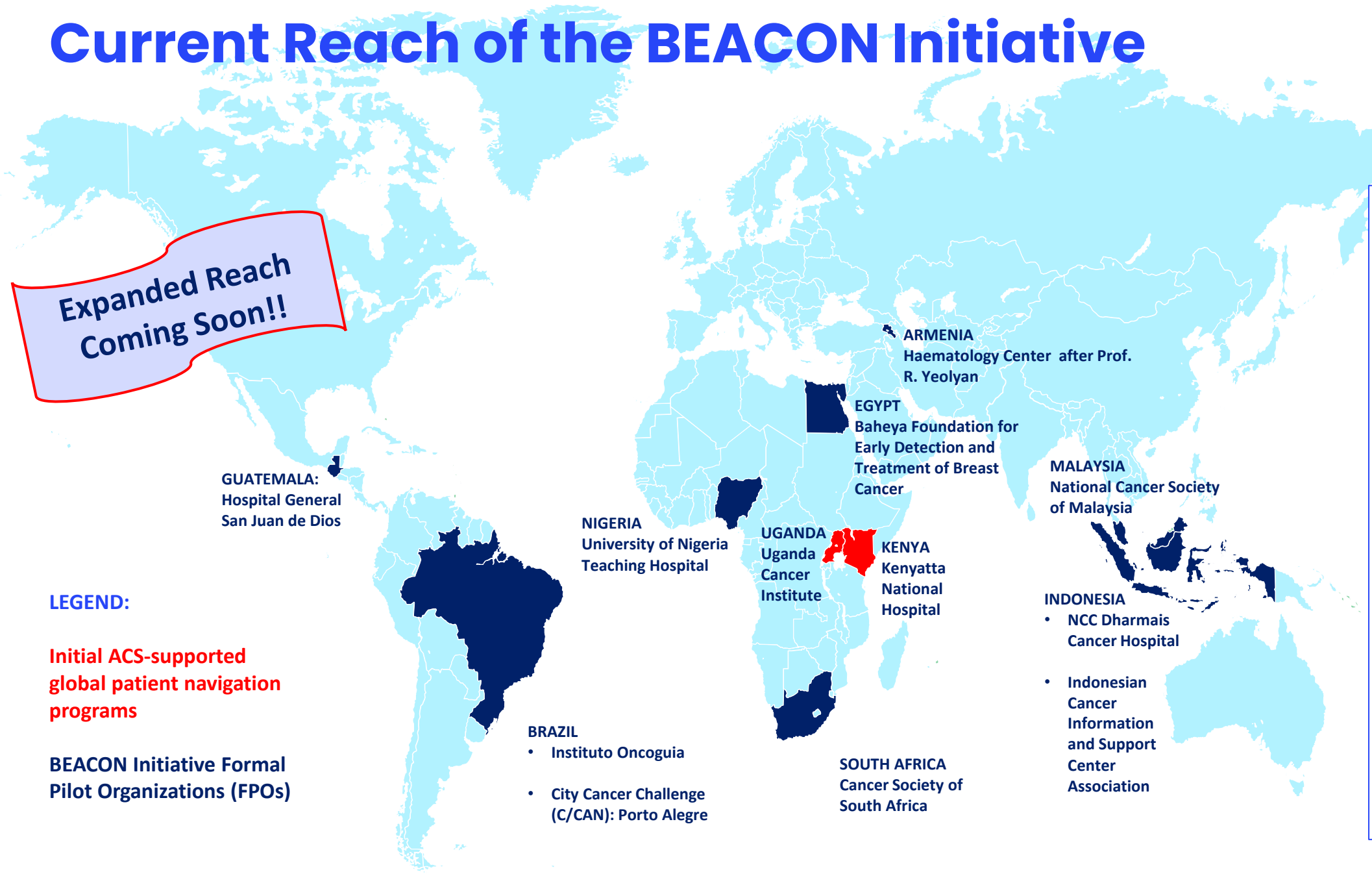
Even though the Toolkit itself-service, interactions with others is a part of the experience!

The Toolkit is bolstered by a variety of virtual engagements and a digital platform where users:

Reflect on	experiences and challenges
Encourage	each other in the process
Exchange	resources developed
Generate	ideas and problem-solve together

Through the BEACON Initiative, we are widening the circle and cultivating and connecting a global network of oncology patient navigation practitioners.

Current Reach of the BEACON Initiative



ACS BEACON Initiative *by the Numbers*

FEBRUARY 10, 2022-
JANUARY 31, 2023

GENERAL

14 Total Number of LMICs

TOOLKIT

1636 Total Number of Toolkit Sessions

VIRTUAL EVENTS

20 Number of Virtual Events (VE)

141 Number of Unique VE Participants

DIGITAL PLATFORM

137 Number Accessing Digital Platform and Toolkit

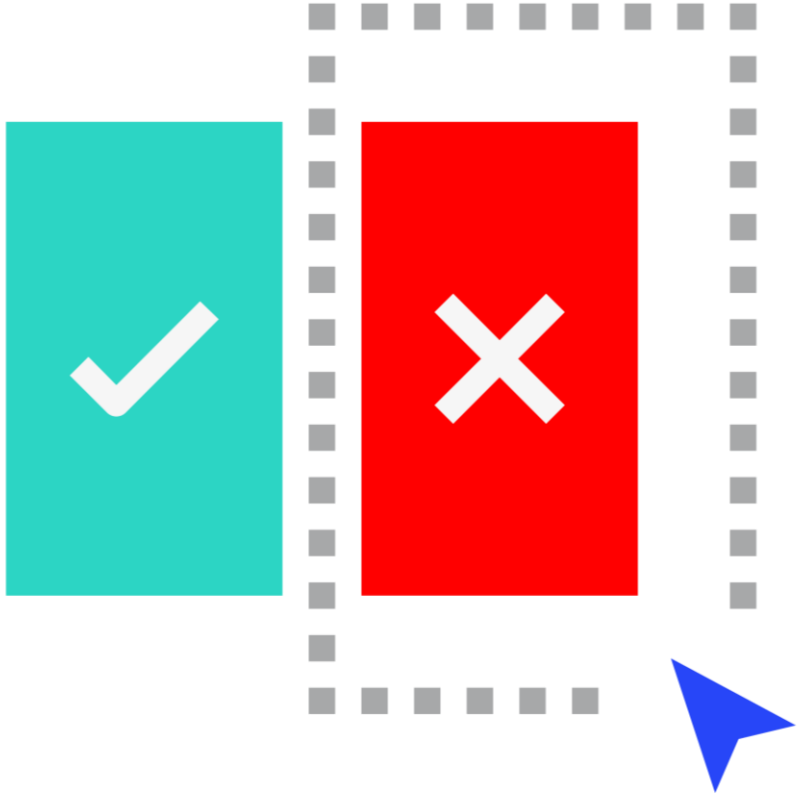
Qualitative Feedback on the Toolkit from Pilot Users

- *"We are expecting to have guidance for creating a cancer PN program. ACS provided it for us. It has exceeded our expectations in some parts, we weren't expecting a grant."*
- *"It's a very systematic way to show how you can do this. It shows you the main points, where you have to focus."*
- *"I love the video. The intro video on what you can expect from the section. We do follow the video; the end of the video shows us the goal. We have to really internalize the video introduction of the section. More videos, please! We can see what we're going to have at the end of the video. We are confident starting because we know the path."*
- *"The interaction between presenters, ACS and other organizations, discussing the use of the toolkit in the real-world setting..... The contextualization was really helpful in being able to understand how to use the resources better."*
- *"It was interesting to see the similarities and differences between each organization's PN programs. As always, the sharing by the wider audience during the Q&A session was incredibly helpful."*
- *" I find this webinar valuable in the way that I get to know better the patient navigation program[s] in other countries ..... and how we can learn from one another."*

Current Limitations of Toolkit

Focused on serving users:

- building patient navigation programs **for the treatment phase** of the cancer journey *(though content is adaptable to other phases)*
- within **individual health facilities and cancer organizations to build responsive programs** rather than policy makers and cancer control planners
- who can work primarily **in English**
- Focused on all cancers generally *(rather than specific cancer types/ patient populations)*



We would like to expand BEACON in the future to address these limitations and we are seeking resources for doing so!

Global Patient Navigation Indicators

Patients Served

- **Total number of new cancer patients navigated annually**
- **Total number of new cancer patients navigated to date**

Navigation Services Provided

- **Total number of navigation encounters provided annually**

Global Patient Navigation Indicators

Indicator No.	Indicator	Type	Definition	Rationale
A. Patients Served				
A1	Total number of new cancer patients navigated annually	Output *Period-specific*	Total number of patients with a first *navigation encounter* per year	Provides an overview of the volume of new cancer patients entering in the system and benefitting from the program each year. Annual trends can inform whether *new patients* are increasing or decreasing.
A2	Total number of new cancer patients navigated to date	Output *Cumulative*	Total number of patients with first navigation encounter since program launch	Provides an overview of the volume of cancer patients served by the program since its inception over the life of the program.
A3	Total number of unique cancer patients navigated annually	Output *Period-specific*	Total number of *unique patients* who have had at least one face-to-face navigation encounter per year	Provides an overview of the volume of cancer patients served by the program each year. This will also assist with calculating program cost per patient per year and over time. *Navigation encounter will be defined by each program (i.e., clinical navigation, resource navigation, etc.).*
A4	Total number of unique cancer patients navigated to date	Output *Cumulative*	Total number of unique patients who have had at least one face-to-face navigation encounter since program launch	Provides an overview of the volume of cancer patients served by the program since its inception over the life of the program.
B. Navigation Services Provided				
B5	Total number of navigation encounters provided annually	Output *Period-specific*	Total number of face-to-face navigation encounters provided annually	Provides an overview of the number of face-to-face navigation encounters provided to patients and an overall snapshot of the services provided at the program level. *Navigation encounter will be defined by each program (i.e., clinical navigation, resource navigation, etc.).* *Can be disaggregated by navigation type.*

Obote Amos
Program Manager, Patient Navigation

Uganda Cancer Institute

Presence of Patient Navigation in NCCPs

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SSD 4.3.8. Establish/ Strengthen follow up of patients commenced on treatment							
4.3.8.1. Introduce a system to reduce loss to follow up	Introduce a follow up chart and loss to follow up registers in each treatment center to monitor follow up care	DDG-NCD, D-NCCP, Hospital Directors		X			
	Lobby to develop a patient navigation system which ensure confidentiality	DDG-NCD, DDG-MS, DDG-DS, D-NCCP, Patient support groups		X			
	Develop linkages with survivor care teams, rehabilitation care teams and palliative care teams, private hospitals and clinics, hospices, patient support groups maintaining confidentiality	D-NCCP		X			

National Strategic Plan on Prevention and Control of Cancer in Sri Lanka (2020-2024)

Stakeholder	Role of stakeholder	Current status	Interest in Issue	Influence	Position	Impact
Cabinet	• Providing overall policy direction on health • Adequate resource allocation for cancer prevention, diagnosis, and treatment • Ensuring the health and productivity of the population • Prioritisation of cancers and resource mobilization • Provision of infrastructure and equipment for screening, diagnosis and treatment • Create framework contracts for procurement of cancer drugs • Ensure that the general population has access to information and to cancer services as close to the family residence as possible • Provide overall policy direction on cancer control cancer and its implementation • To have a well-defined and functional cancer patient navigation and referral system	• Lack of a national cancer control policy • Inadequate funding and structured support from partners.	High	High	Supportive	High

National Cancer Control Strategic Plan Zambia (2016-2021)

Introducing and Integrating Patient Navigation into Your Country's Cancer Care Delivery System: Discussion Questions

1. **How is patient navigation included in your NCCP (if at all) and in what section(s) of the plan?**

2. **What is your current strategy for introducing or expanding patient navigation as part of cancer control and care delivery services?**
   - Are there any patient navigation programs that already exist whose experiences you can build off of? *(If yes, what exists? If no, where/how do you plan to start?)*
   - Do you have any specific policies in place (e.g., national/regional level or facility-level) to support the delivery and expansion of patient navigation? *(If not, is there a plan for a policies?)*
   - What data (including patient needs assessments), can you draw upon to promote patient navigation?

3. **What is the capacity (money and staff) of your country to provide, expand, start patient navigation programs throughout the country?**
   - What are your future plans and whose support do you need?

Overview of Global Cancer Education Materials for Patients and Caregivers (CEMPC)

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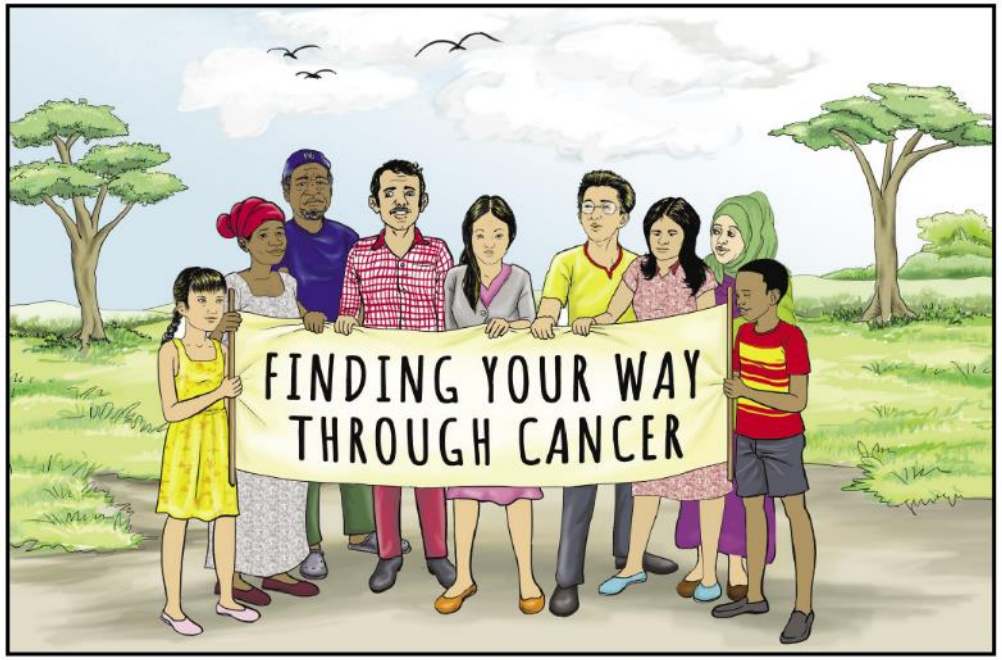
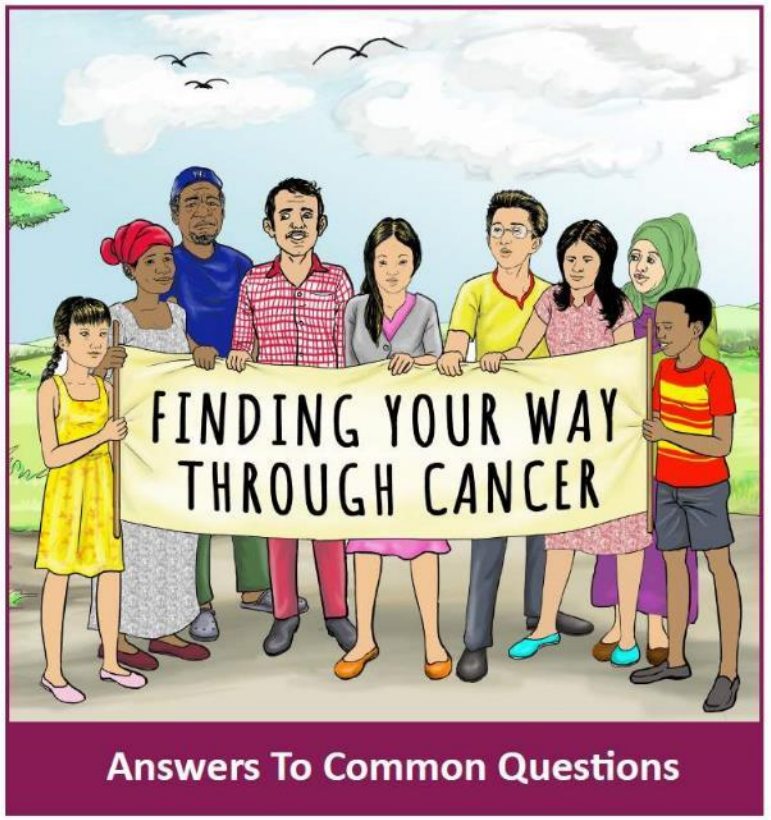
Health Worker Flipchart



A Flipchart for Cancer Education

"It's interesting. It gives hope. For example, here where I read that 'Why me?'... I like it there because I realized that I am not the only one who asks these questions."

Patient and Caregiver Booklet

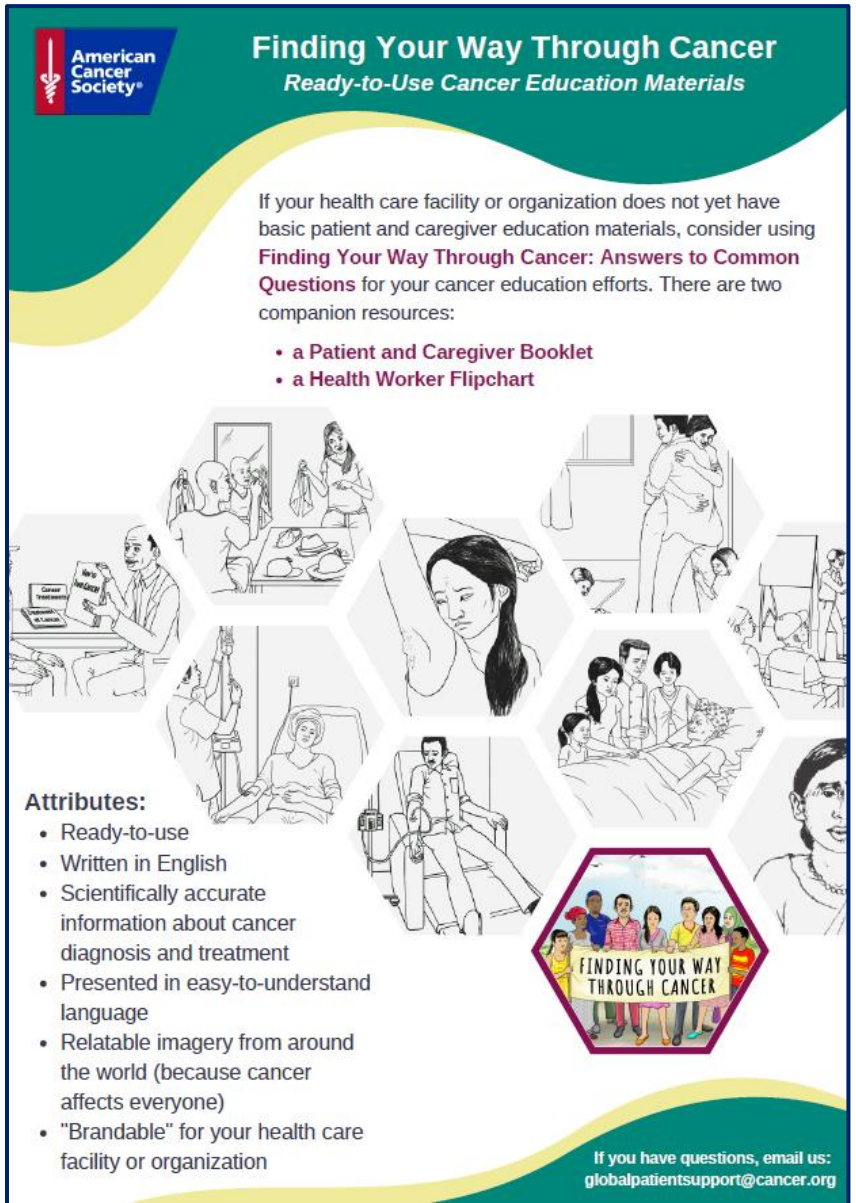


How to Gain Access to these Materials Today!

Digital and **print use** copies of these materials in English are available for download at:

cancer.org/globalpatientsupport

These materials will be available in **African Portuguese** and **French** later this year, in time for **AORTIC 2023**. Other languages in the pipeline (as resources permit) include **Arabic, Brazilian Portuguese,** and **Spanish.**



Learn More on Your Own Time!

Click on the links below to watch or share short introductory videos

Introduction to Patient Navigation and the ACS BEACON Initiative:

https://youtu.be/UGQdhOGScEk

The History of Patient Navigation:

https://youtu.be/tIEmfZauEbY

Introduction to the ACS BEACON Initiative Global Patient Navigation Toolkit and Virtual Community Platform

https://youtu.be/AW-mxCvDwQQ

Expanded Reach Coming Soon!!

We will open the BEACON Initiative to new users in August 2023.

Please let us know if your organization or health facility would like to join our wait list and receive information in June on how to apply. Send an email to: acs.beacon@cancer.org.

ACS BEACON website: https://beaconcommunity.cancer.org/s/about-acs-beacon-public

"I am thrilled to see that patient navigation is gaining worldwide application, and as an effective process and strategy to reduce cancer disparities in America as well as in in many other parts of the world. The American Cancer Society has played and continues to play an essential role in making all this happen."

-Dr. Harold Freeman, Father of Patient Navigation

Cancer patients staying at an ACS partner patient hostel in Kampala, Uganda while undergoing several months of treatment.

Thank You

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http://www.cancer.org/globalpatientsupport

https://beaconcommunity.cancer.org/s/about-acs-beacon-public