

# Global analysis of metastatic breast cancer policy gaps and proposed solutions

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**World Cancer Congress**  
Kuala Lumpur, Malaysia  
1–4 Oct 2018

Strengthen  
Inspire  
Deliver



Initiatives to Support the Patient Journey

Track 4 - Maximizing quality of life and death.  
Empowering patients and care givers

Disclosure of interest: None declared

# Objectives

Increasing support for metastatic breast cancer but remaining **high patient unmet need**

Policy support along the patient journey is **driven by National Cancer Control Plans (NCCPs)** and complemented by public and non-public action

Increased support for detection, awareness and screening but remaining **limited success in detection and diagnosis programs** and treatment

To address these gaps, we investigate the role of **multi-stakeholder action** in support for policy development



1

Understand breast cancer (BC)/mBC policy development in 16 countries and identify opportunities for improvement

2

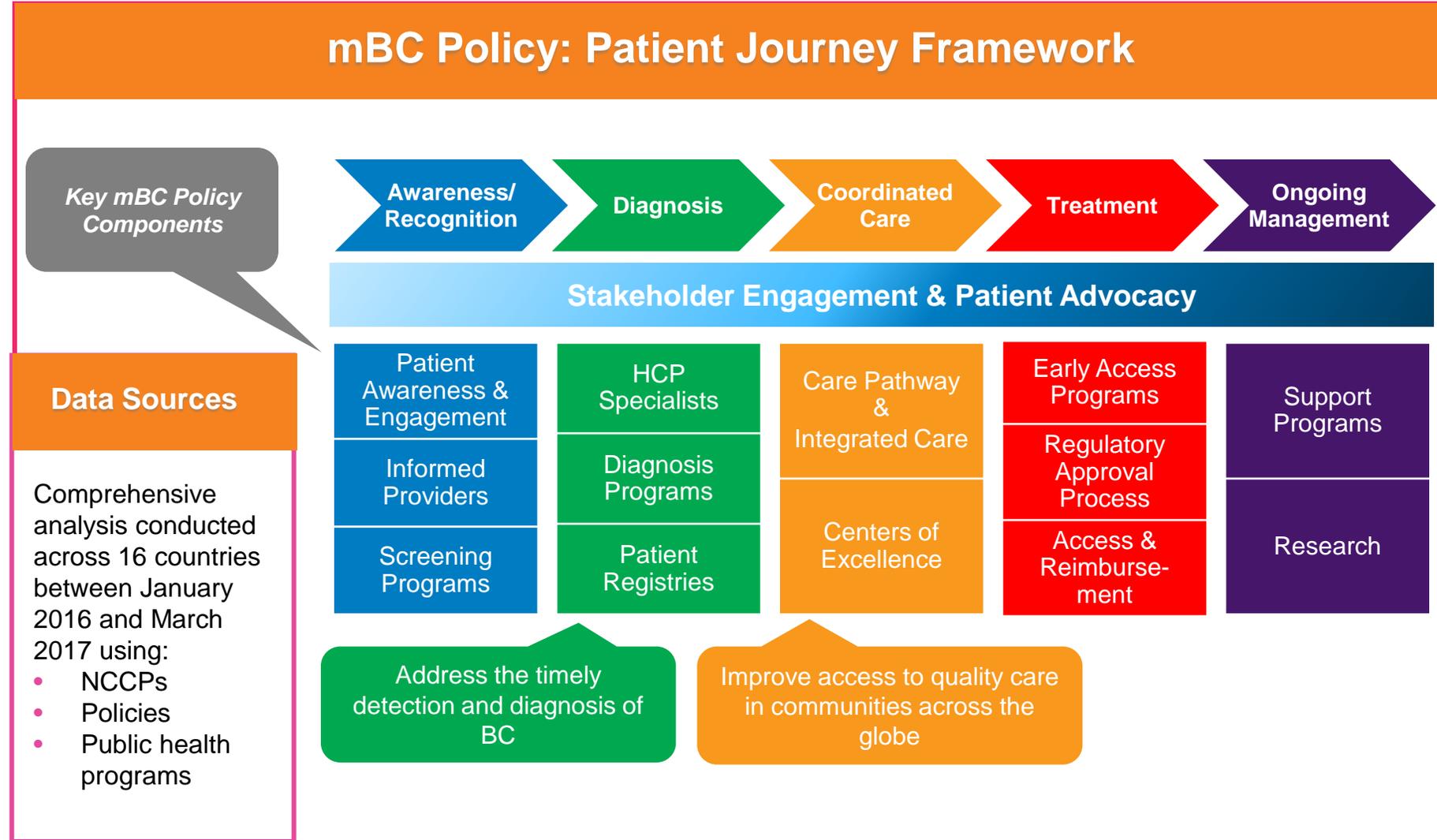
Illustrate promising practices spearheaded by civil society (NGOs and academia) that demonstrate success addressing identified gaps and exemplify models for replication

3

Establish the importance of stakeholder collaboration to implement policies that support timely BC/mBC detection and treatment initiation

# Approach

- We aligned policy and advocacy research to investigate the key needs of mBC patients in 16 countries across five dimensions.
- We evaluated using standardized criteria measuring the adoption and implementation of NCCP goals and BC-specific policies and advocacy programs.
- Across each stage, examples of advocacy initiatives and models of promising practices were extracted from Susan G. Komen's global portfolio



# Results

	AMERICAS				EUROPE							AFME			ASIA	
mBC Policy Component	BR	CA	CHL	MX*	DE	EN	FR	IT	NL	PL	SE	MO	UAE	TZ	JP	KR
<b>NCCP in Place?</b>	✓	✓	✓	X	✓	✓	✓	✓	X	✓	✓	✓	X**	✓	✓	✓
<b>Awareness/Recognition</b>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
<b>Diagnosis</b>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
<b>Coordinated Care</b>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
<b>Treatment</b>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
<b>Ongoing Management</b>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●

Development Level Key

● High    ● Moderate    ● Low

# Awareness and recognition

Programs include awareness campaigns, public and HCP education and patient guides

## Key Policy message

- Awareness of BC risk factors and early signs is recognized in most countries with a NCCP in place
- Public awareness and education programs specific to mBC (or advanced cancer in general) remain a small part of general cancer and BC initiative across all 16 countries
- In high income countries are being expanded to include mBC-focused agendas and actions

# Awareness and recognition

## BEST PRACTICE



The German Cancer Society (DKG) and German Society of Senology (DGS) developed service delivery-related requirements, and implement basic and continuing education for HCPs, to ensure that breast centers maintain their accreditation.

## PROMISING PRACTICE



In China, the Pink Roses educational toolkit with emphasis on both early and advanced disease, educates patients and HCP in breast cancer risk factors, efficient referral and timely diagnosis.

# Diagnosis

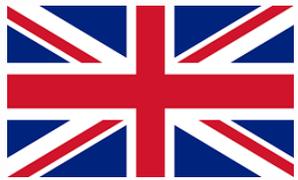
Health care practitioners  
specialists, diagnosis  
programs, patient  
registries

## Key Policy message

- Timely, effective BC diagnosis is contingent upon the availability of skilled HCPs in oncology, radiology, and pathology.
- All NCCPs recognize the need to develop capacity of health systems to effectively diagnose patients. Policies tend to be general, with focus on eBC.
- National cancer registries provide policymakers with critical information on patient data, progress and outcomes to help inform policy decisions
- The countries examined lack a systematic collection of mBC patient data

# Diagnosis

## BEST PRACTICES



Breast Cancer Care (UK)'S Secondary Breast Cancer Taskforce helped ensure the mandatory collection of data on mBC incidence and survival

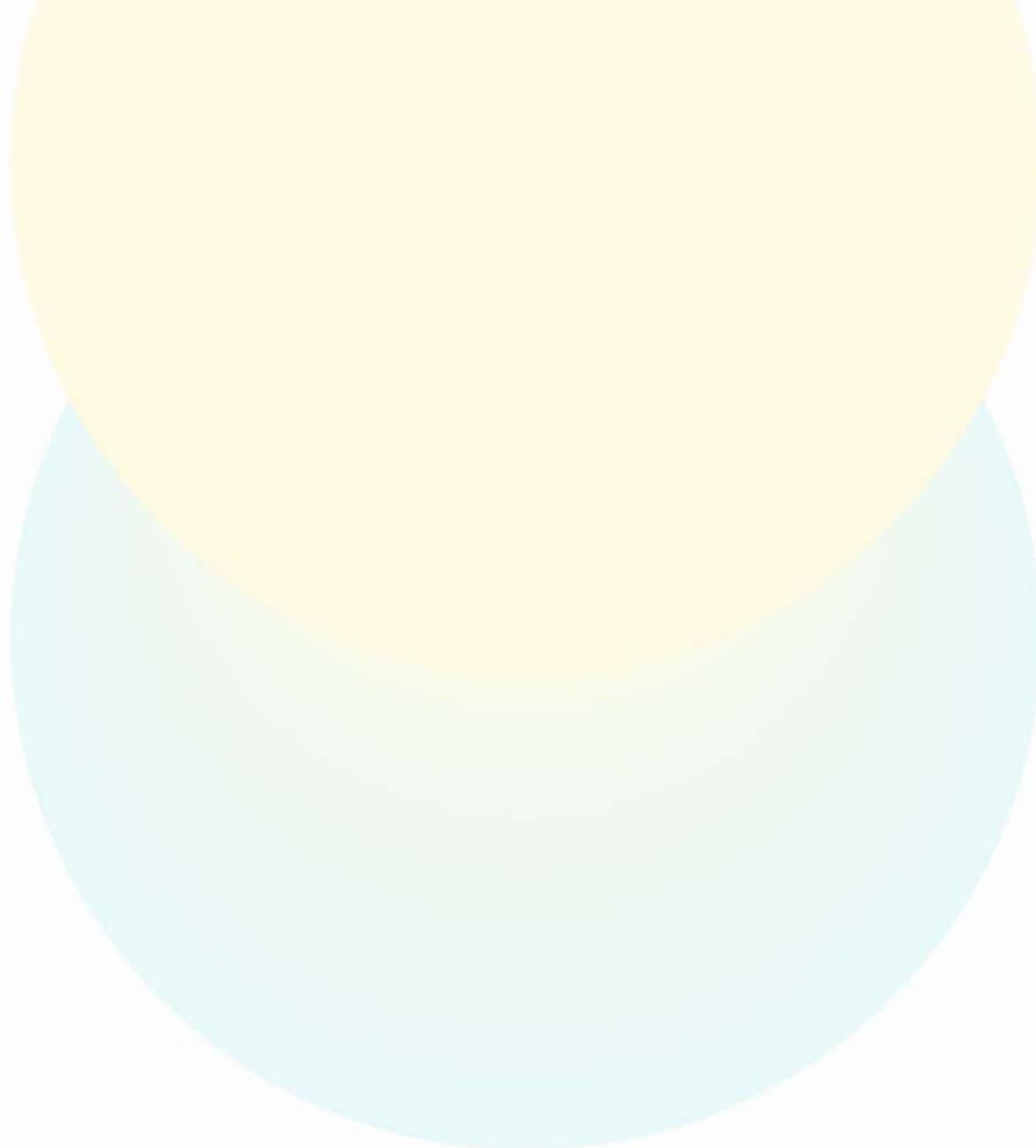


In Germany, an ongoing population-based cohort study called the Tumor Registry Breast Cancer collects data on mBC patients

## PROMISING PRACTICE



A program in Sergipe, Brazil - Integrated Approach to Improving Oncology Care (IAIOCA) – helped improve breast cancer diagnosis and access to oncology care



# Coordinated care

Integrated care &  
Centers of Excellence

## Key Policy message

- Integrated care pathways provide a patient-centered, holistic approach to BC and mBC treatment that improves outcomes and care efficiency
- CoE exemplify best practices in coordinated research and cancer care, serving as a model of comprehensive care and a resource for multidisciplinary treatment and training
- In ~75% of countries analyzed, integrated care pathways are driven by government initiatives, despite being supported and often implemented by NGOs

# Coordinated care

## BEST PRACTICES



Tawam Hospital (UAE) is the main national oncology center and a regional patient referral center. Only hospital in the UAE with an established palliative care program



European legislation mandates that Breast Cancer Centers must adhere to strict diagnosis guidelines and timelines to maintain their status. In 2016 this was extended to include patients with mBC



In Italy, diagnosis and treatment in certified or accredited BC Units is linked to reimbursement to encourage efficient and standardized BC and mBC care across the country

## PROMISING PRACTICE



Collaborative platform of cross-sectorial stakeholders to develop early diagnosis and treatment guidelines, to increase the capacity to address BC in Tanzania

# Treatment

Early Access  
Programs

Regulatory approval  
process

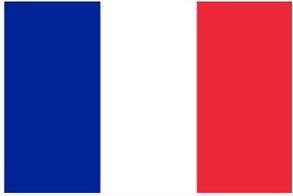
Access &  
Reimbursement

## Key Policy message

- Early access programs provide patients with timely access to the latest innovations in cancer care, prior to full regulatory approval.
- NCCPs we assessed highlight the guiding principles of fast and equitable access to treatments, however only few provide clear recommendations on how to achieve this.
- Almost 70% of the examined countries have early access schemes that allow flexible access prior to regulatory approval, particularly in areas with important unmet needs and of major public interest.

# Treatment

## BEST PRACTICES



There are no schemes dedicated to improving early access to eBC and mBC treatments. The Temporary Authorization of Use (ATU) program in France, provides access to drugs aimed at treating severe diseases not yet covered by a marketing authorization



EMA provides early dialogue, accelerated and flexible regulatory authorization for highly innovative medicines



The Italian system uses managed entry agreements (MEAs), which are confidential schemes between the manufacturer and AIFA or the region that make provisions from simple discounts to cost sharing, risk sharing price volume deals and pay for performance schemes



A breast cancer clinical trial helpline in the USA provides breast cancer patients and others affected with BC with an on-demand support network and works with a Metastatic Trial Search tool to bridge the information gap regarding access to innovative treatment options

# Ongoing management

Support programs and research

## Key Policy message

- Support programs represent the provision of cancer care to patients at any point during the continuum of care, including support programs, rehabilitation and palliative care.
- Research is critical to supporting the improvement of treatments and other care products, procedures and services for BC and other cancers.
- Research on mBC articles is generally less common (about 7% of all BC published research articles)

# Ongoing management

## BEST PRACTICES



The Middle East Cancer Consortium seeks to resolve the scarcity of palliative care by offering training and resources for oncology professionals. The objective is to broaden acceptance of such programs in the region by balancing cultural issues of religion and stigma and financial concerns around the cost of medicines

## PROMISING PRACTICES



Europa Donna, in collaboration with Breast International Group, launched AURORA in 2013, an innovative mBC research program

### African Breast Cancer - Disparities in Outcomes (ABC-DO) Study



The ABC-DO is a multi country partnership to invest in local data collection and analysis of across the patient journey. In five public hospitals ABC-DO examines the full journey of breast cancer patients, from pre-diagnosis through the post-diagnosis treatment period for up to 3 years.

# Conclusions



mBC  
development

**Significant development in the policy environment for BC across countries.** Policy lags behind in mBC targeted advances. NCCPs refer to cancer as one disease area and no specific BC/mBC action



Variability

**Differences exist across countries of similar or different development levels.** Better progress in awareness and provision of care. Limited progress in diagnosis and treatment remains challenging.



Collaboration

**Success depends on collaboration between all stakeholders and sharing experiences across countries (both success and failures).** Crucial contribution is provided by advocacy, patient organizations and industry. Official national and international action is indispensable

# Thank you!

## Questions?

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# Breast Cancer Initiative 2.5 (BCI2.5)

A global campaign to reduce disparities in Breast Cancer Outcomes

## Allison Ekberg Dvaladze, MPH

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Disclosure of interest: None declared

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**BREAST  
CANCER  
INITIATIVE 2.5**

Making breast health a global priority



PHOTO CREDIT: CAROLYN  
TAYLOR

# BREAST CANCER PATIENT

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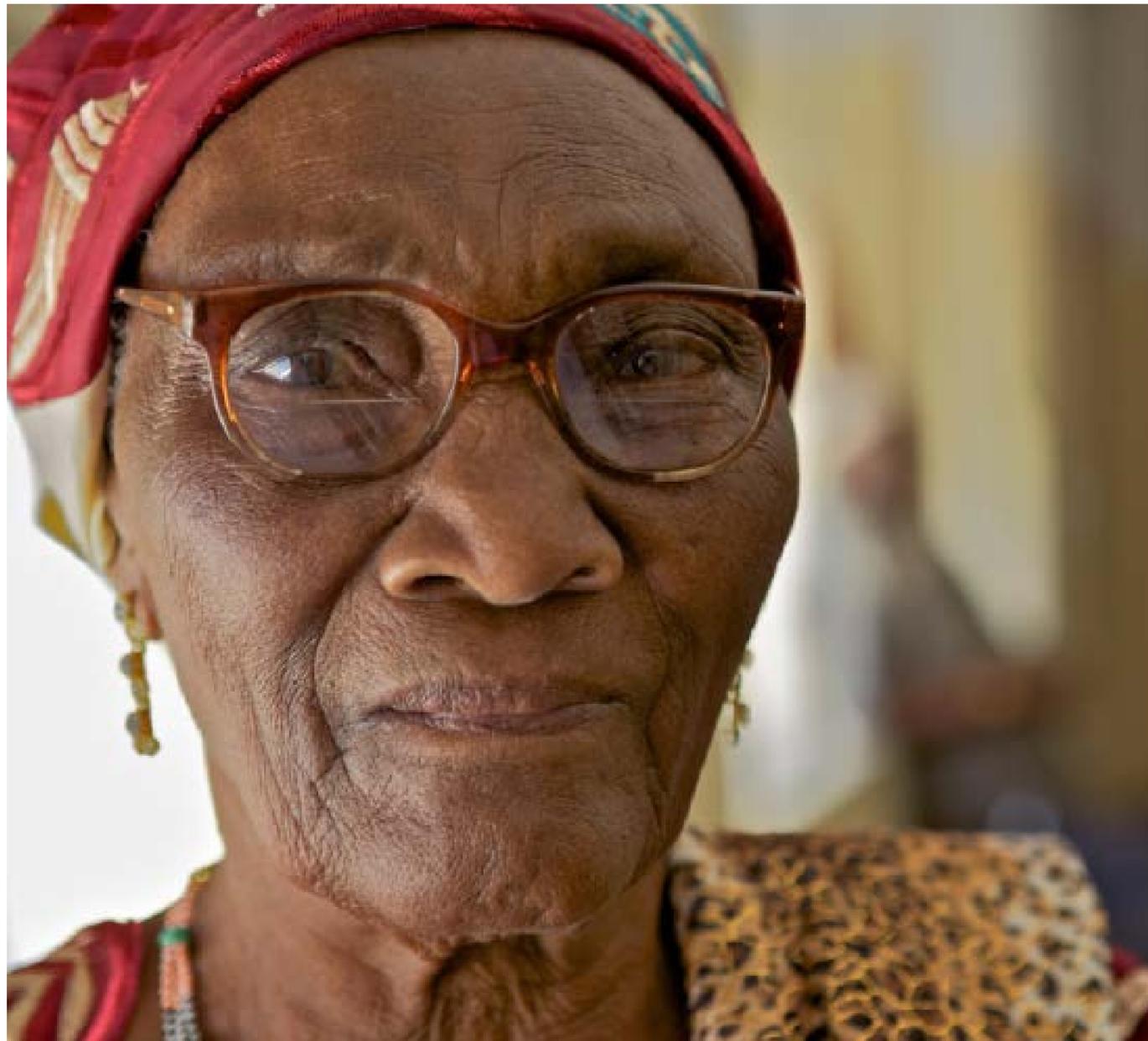


PHOTO CREDIT: CAROLYN TAYLOR

A photograph of a busy hospital ward, likely a maternity or pediatric unit, with many patients and staff. The image is overlaid with a semi-transparent pink filter. The text "TOOLS AND RESOURCES" is centered in white, bold, uppercase letters, with a thin white horizontal line underneath it.

# TOOLS AND RESOURCES

# BCI2.5 ([www.bci25.org](http://www.bci25.org))



## ABOUT

### Empowering Champions

BCI2.5 is uniting the global breast cancer community behind a common goal to make breast health a global priority and reduce disparities in breast cancer outcomes for 2.5 million women by 2025.



## KNOWLEDGE SUMMARIES

### Breast Cancer Control

Tools to foster discussion and assist policy makers, clinicians and advocates in identifying and prioritizing resource-appropriate interventions in the planning and development of breast cancer control programs.



## DATA MAPPING

### GloBAM

The Global Breast Health Analytics Map is an interactive data visualization tool for analyzing the determinants of the global breast cancer burden.



## MULTIMEDIA

### Educational Resources

A growing e-library featuring webinars, videos, course materials and more addressing issues that span the breast cancer continuum from planning to palliative care.



## ASSESSMENT TOOLS AND REPORTS

### Situation Analysis

BCI2.5 self-assessment tools aid institutions and countries in assessing need, identifying bottlenecks in breast health care delivery and determining appropriate interventions in specific settings.



## FOUNDING ORGANIZATIONS

### Global Support

The initiative began as a call for action in 2014, supported by the American Cancer Society, Susan G. Komen® and the Union for International Cancer Control. The initiative is inclusive and encourages organizations, institutions and countries to connect and join the effort.

# GLOBAL BREAST HEALTH ANALYTICS MAP (GLOBAM)

Global Breast Health Analytics Map (GloBAM)
Map Compare Download Data Sources

Statistic: Breast cancer incidence (age standardized rate) Click on a country to view details. Zoom with icons to left of map.

Global Breast Health Analytics Map (GloBAM) | Map Compare Download Data Sources About

What would you like to compare? Countries | Statistics

Health expenditure per capita (current US\$) | 
 Breast cancer incidence (age standardized rate) | 
 Breast cancer mortality (cumulative risk) | 
 Compare Statistics | Clear

Comparison\* of [Health expenditure per capita \(current US\\$\)](#), [Breast cancer incidence \(age standardized rate\)](#), and [Breast cancer mortality \(cumulative risk\)](#)

Country	Health expenditure per capita (current US\$)	Breast cancer incidence (age standardized rate)	Breast cancer mortality (cumulative risk)
Afghanistan	54.96	35.10	2.31
Albania	239.58	53.90	1.68
Algeria	313.52	48.50	1.86
Angola	267.22	23.50	1.30
Argentina	1074.07	71.20	2.24
Armenia	158.62	74.10	2.78
Australia	6109.82	86	1.48
Austria	5427.26	68	1.51
Azerbaijan	436.02	25.40	0.97
Bahamas	1620.68	98.90	2.71
Bahrain	1067.20	42.50	1.19
Bangladesh	31.63	21.70	1.15
Barbados	1007.22	94.70	2.41
Belarus	462.88	45.90	1.67
Belgium	5092.60	111.90	2.22

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**Ghana Snapshot**

ISO Code	GH
WHO Defined Region	Sub-Saharan Africa
Income Status	Lower middle income
<b>Breast cancer incidence (cumulative risk)</b>	<b>2.72</b>
Avg of all Sub-Saharan Africa countries	2.79
Avg of all lower middle income countries	3.31

[Ghana details...](#) | 
 [Compare Ghana...](#)

[Close](#)

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**TANZANIA BREAST  
HEALTH CARE  
ASSESSMENT  
2017**

An Assessment of Breast Cancer  
Early Detection, Diagnosis and  
Treatment in Tanzania



**SERGIPE 2018:  
BREAST HEALTHCARE  
ASSESSMENT**

An Assessment of Breast Cancer  
Early Detection, Diagnosis and  
Treatment in Sergipe, Brazil



# RESOURCE STRATIFICATION

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**BASIC LEVEL:** Core resources or fundamental services necessary for any breast health care system to function. Typically applied in a single clinical interaction.

**LIMITED LEVEL:** Resources or services are attainable with limited financial means and modest infrastructure and produce major improvements in outcome such as survival.

**ENHANCED LEVEL:** Resources or services that are optional but important, because they increase the number and quality of therapeutic options and patient choice and improve outcomes.

**MAXIMAL LEVEL:** Services used in some high resource countries that have *lower priority* on the basis of extreme cost and/or impracticality.



# RESOURCE STRATIFICATION

Table 1. Resource-stratified pathway for breast cancer early detection and screening programs.

	Level of Available Resources			
	Basic (Level 1)	Limited (Level 2)	Enhanced (Level 3)	Maximal (Level 4)
<b>Public Education and Awareness</b>	Development of culturally sensitive, linguistically appropriate local education programs for target populations to teach value of early detection, breast cancer risk factors and breast health awareness (education + breast health awareness)	Culturally and linguistically appropriate targeted outreach/ education encouraging CBE for age groups at higher risk administered at district/provincial level using healthcare providers in the field	Regional awareness programs regarding breast health linked to general health and women's health programs	National awareness campaigns regarding breast health using media
<b>Detection Method</b>	Clinical history and CBE	Diagnostic breast US +/- diagnostic mammography in women with positive CBE  Mammographic screening of target group	Mammographic screening every 2 years in women ages 50-69  Consider mammographic screening every 12-18 months in women ages 40-49	Consider annual mammographic screening in women ages 40 and older  Other imaging technologies as appropriate for high-risk groups
<b>Evaluation Goal</b>	Breast health awareness regarding value of early detection in improving breast cancer outcome	Downsizing of symptomatic disease	Downsizing and / or down-staging of asymptomatic disease in women in highest yield target groups	Downsizing and/or down-staging of asymptomatic disease in women in all risk groups

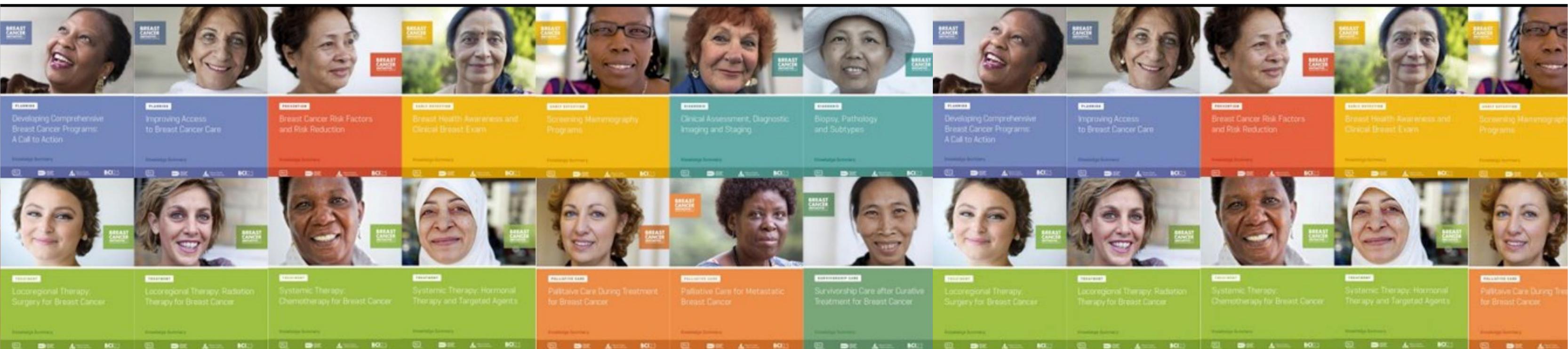
Adapted from the Breast Health Global Initiative (BHGI) guidelines, 2008



# KNOWLEDGE SUMMARIES

## FOR COMPREHENSIVE BREAST CANCER CONTROL

Tools to foster discussion and assist policy makers, clinicians and advocates in identifying and prioritizing resource-appropriate interventions in the planning and development of breast cancer control programs.

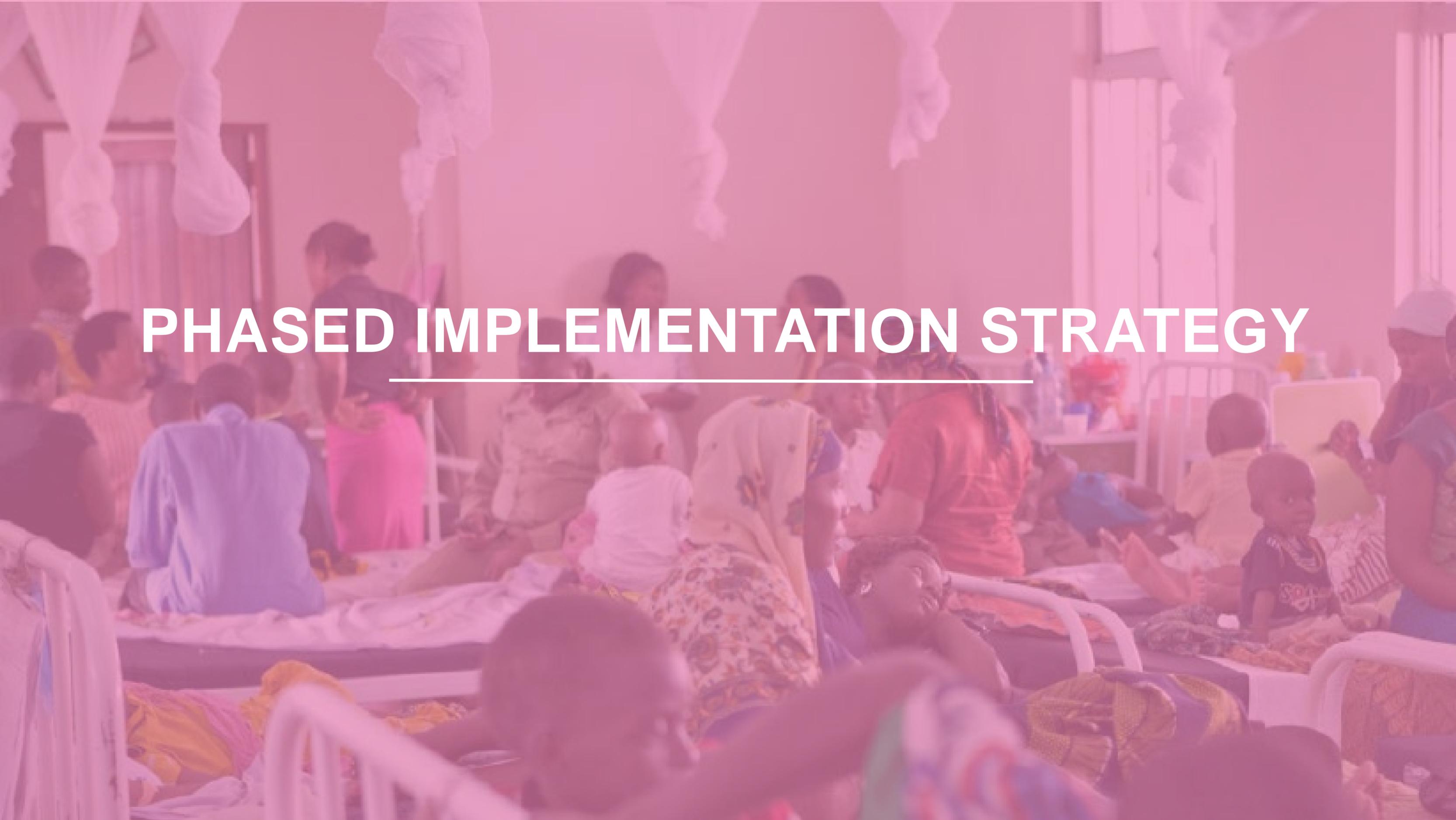


A multi-year collaboration led by the Union for International Cancer Control; Breast Health Global Initiative (BHGI), which is based at the Fred Hutchinson Cancer Research Center in Seattle, Washington; and the Center for Global Health at the U.S. National Cancer Institute. This effort supports the goals of the BCI2.5 campaign to make breast health a global priority and reduce disparities in breast cancer outcomes.



# PHASED IMPLEMENTATION STRATEGY

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# FOUNDATIONAL PREREQUISITES

Conduct assessment of existing clinical capacity, practices, referral systems, guidelines, protocols and patient barriers

## REFERRAL/PATIENT PATHWAYS

Develop resource-appropriate standardized guidelines and protocols for all aspects of breast health care in the Tanzania health system.

## TRAINED WORKFORCE



## SITUATIONAL ANALYSIS

Strengthen processes to ensure an effective continuum of care for the patient, including appropriate referral processes and patient tracking.

## GUIDELINES & PROTOCOLS

Develop an informed and properly trained health care workforce

# MANAGEMENT OF PALPABLE DISEASE

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**Systematic triage and management of palpable breast disease.** A systematic approach to navigate patients with palpable (symptomatic) breast disease through a process of clinical evaluation, diagnostic imaging and tissue sampling to accurately distinguish benign from malignant breast disease and manage (treat/palliate) accordingly.

# STRENGTHENING PATIENT PATHWAYS & NAVIGATION



Strengthening of resource-appropriate patient-centric care pathways (treatment planning and navigation) and reducing access barriers.

These organized pathways guide patient navigation through the health system, promote clinical assessment of palpable masses, provide tissue sampling of suspicious masses and initiate prompt treatment for lesions proven to be malignant.

# TRAINING AND EDUCATION SCALE UP

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**Scaling up of targeted education interventions for public and health care staff.** Educational programs to heighten public breast cancer awareness are expanded at the same time that health care personnel are trained in clinical assessment and clinical breast examination (CBE) to promote early diagnosis of clinically detectable disease.

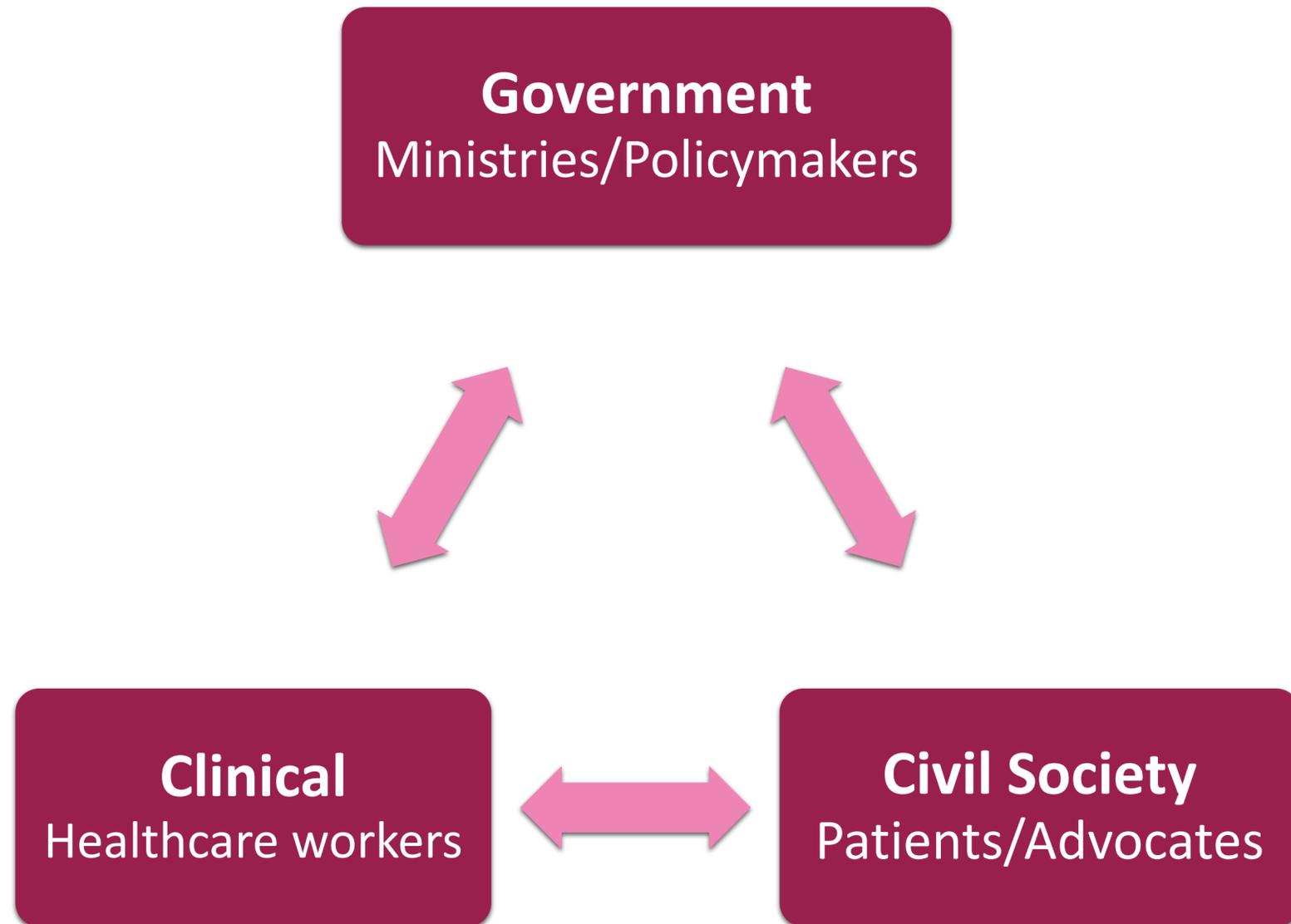
# UPGRADING IMAGE-BASED DIAGNOSTIC SYSTEMS



**Systematic upgrading of image-based diagnostic systems.** Imaging (ultrasound and mammography) is first used for diagnostic work-up of palpable disease. Once this is well established and functional, image-based diagnostic systems can potentially be upgraded (technology, training, quality assurance) for the management of non-palpable/asymptomatic disease as a prerequisite to image-based (mammographic) screening.

# KEY STAKEHOLDERS

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1 | Policy  
Protocols  
Health system

2 | Guidelines  
Education and training  
Technology/equipment

3 | Advocacy  
Education  
Implementation



**we can**

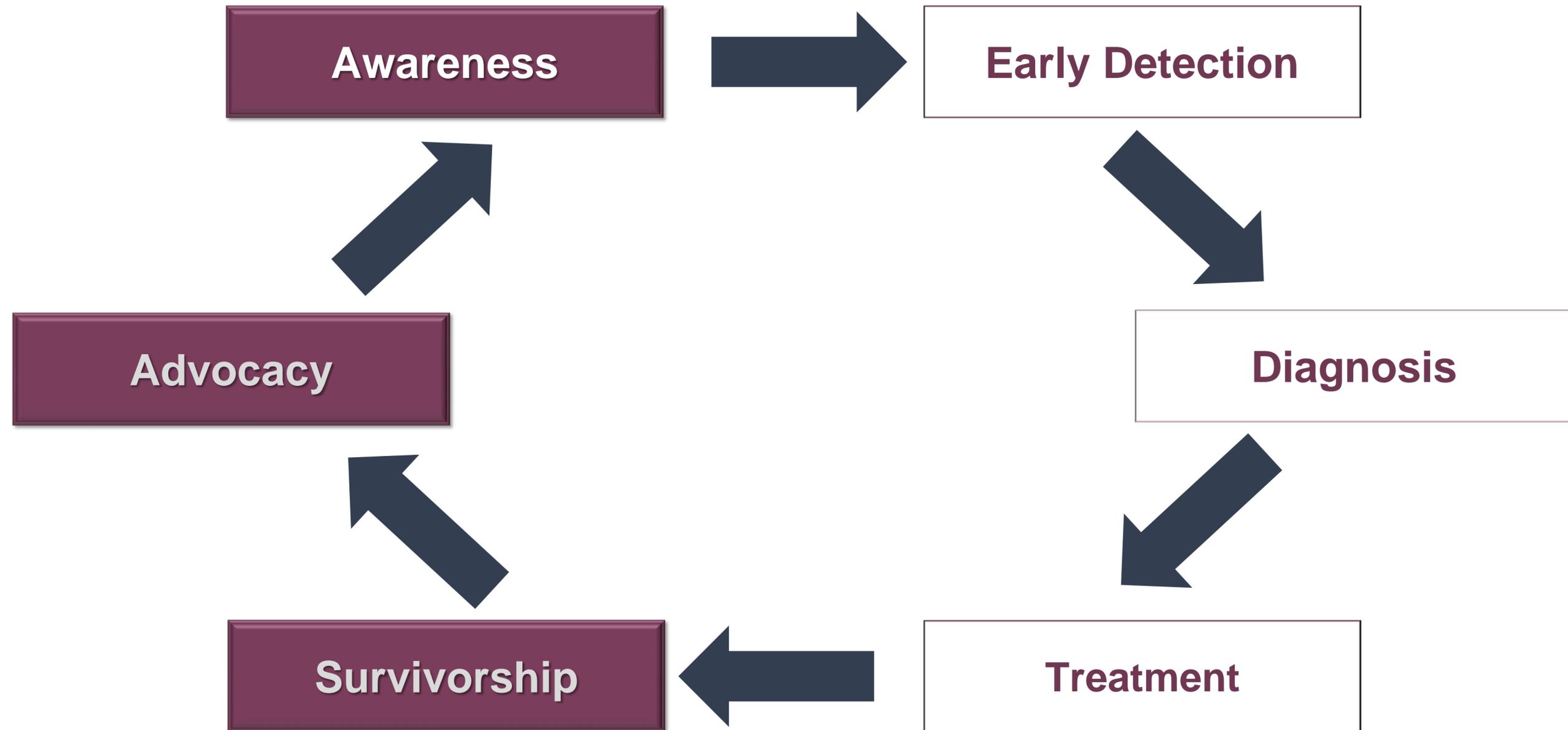
Women's Empowerment  
Cancer Advocacy Network

University of Washington



HỘI THẢO NÂNG CAO CHẤT LƯỢNG CHĂM SÓC &  
CÁC NHÓM HỖ TRỢ BỆNH NHÂN UNG THƯ KHU VỰC CHÂU ĐÔNG  
Nha Trang, 15 tháng 11, 2015

# PUBLIC PARTICIPATION AND HEALTH CARE DELIVERY



# WHERE WE WE CAN AND BCI2.5 WORK



HOME



# THANK YOU

**3rd East Africa Women  
Empowerment Cancer  
Advocacy Network.**

Breast and Cervical Cancer  
Advocacy, Education and  
Outreach Support

**3rd East Africa Women  
Empowerment  
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[www.bci25.org](http://www.bci25.org)



Facebook/BCI25



Women's Empowerment Cancer Advocacy Network



[dvaladze@uw.edu](mailto:dvaladze@uw.edu)



twitter/BCI25



@WeCan\_seattle

BCI2.5

# ICON KEY

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SITUATIONAL ANALYSIS



PRIMARY CARE



COMMUNICATION



BIOPSY



RADIOTHERAPY



HEALTH CARE PROVIDERS



CANCER CENTER



COMMUNITY EDUCATION



PATHOLOGY



PALLIATIVE/PAIN



PROTOCOLS/GUIDELINES



CURRICULUM



CLINICAL BREAST EXAM



SURGERY



PATIENT PATHWAYS



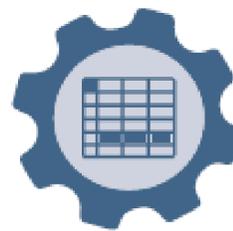
WORK FORCE TRAINING



MAMMOGRAPHY



CHEMOTHERAPY



PATIENT DATA

# Supporting the Patient Journey

**Carolyn Taylor**

Global Focus On Cancer

[carolyn@globalfocusoncancer.org](mailto:carolyn@globalfocusoncancer.org)



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Empowering patients and care givers

**Disclosure of interest: None declared**



*Supporting the Patient Journey*

Global Focus on Cancer

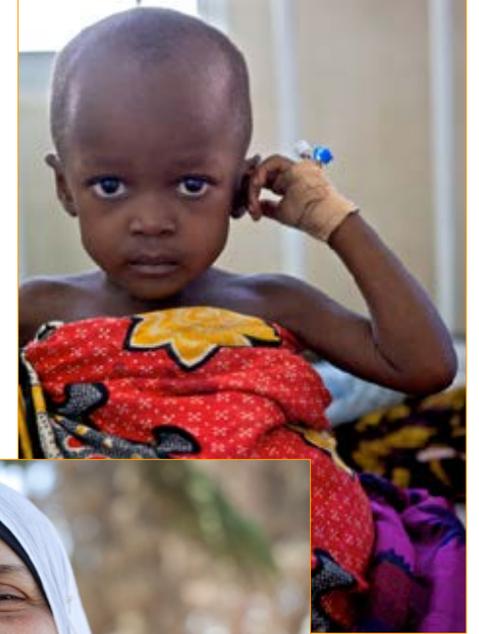
Carolyn Taylor



# Global Focus On Cancer

GFC was formed in 2011 to act as an agent of simple and effective change to help reduce the global burden of cancer.

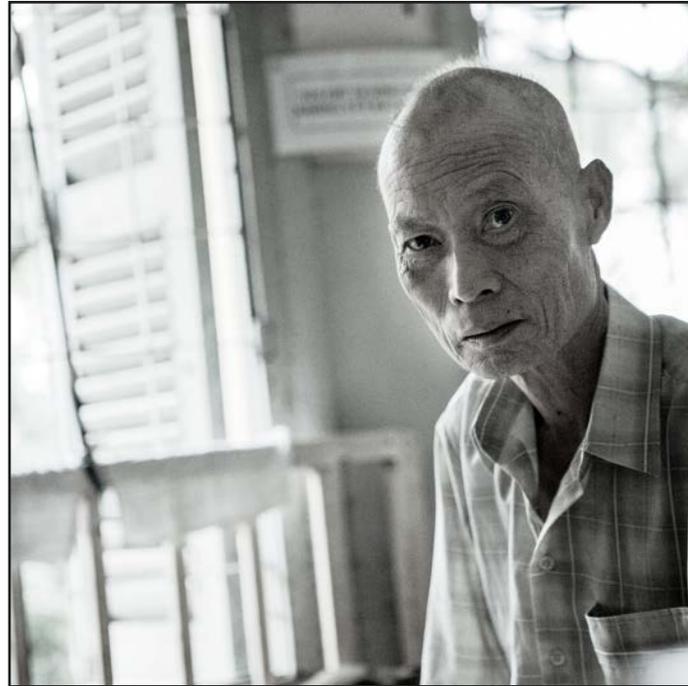
- Awareness programs
- Support programs
- Coalition/alliance building
- Advocacy training
- Networking
- Education



# Challenges:



LIMITED ONCOLOGY RESOURCES



HEALTH LITERACY GAP



LACK OF SUPPORT SERVICES

# Cancer Navigator

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- **Informational support**
    - Infographic and personal narrative videos
    - Cancer basics/Cancer 101
    - Treatment options/side effects
    - Necessary precautions, hygiene, nutrition
  - **Navigational support**
    - Locally available and affordable
      - Housing
      - Food
      - Transportation
  - **Delivery methods**
    - TV/video monitors, stand alone kiosks, tablets
    - Linked to hospital/country web/social media
    - Stand alone YouTube channel
    - Printed materials
- 



# Goals/outcomes:

---

- Fill gaps in education, navigation and awareness
  - Provide practical information specific to cancer & its treatment
  - Encourage patient compliance
  - Ease the burden on hospital staff
  - Reduce patient distress
  - Improved quality of life for patients
- 



# Stronger Together

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- Peer-to-peer support
  - Fill gaps in professional supportive services
  - Give patients a place to voice concerns, receive information specific to their disease
  - Encourage treatment compliance
  - Equip patients with knowledge and resources
  - Ease burden on the overtaxed hospital staff
- Methods
  - Adaption/implementation of an existing, successful peer-peer cancer support program
  - On-site and remote trainings
  - Train-the-trainer model
  - Monitoring and evaluation



## Goals/outcomes:

---

- Improved quality of life for patients
  - Reduce patient distress
  - Increased treatment adherence
  - Improved patient outcomes
  - Increase in cancer awareness among patients and caregivers
  - Reduced burden on hospital staff
  - Increased sense of community and purpose for cancer survivor mentors
- 





**Thank you!**

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# Initiatives to Support the Patient Journey

## October 2, 2018 9:30-11am Room 302-303

Chaired by: Cheng-Har Yip, Cancer Research Malaysia (Malaysia)

**Presentations:**

Anna Cabanes, Susan G. Komen for the Cure (United States)

Allison Dvaladze, University of Washington (United States)

Carolyn Taylor, Global Focus on Cancer (United States)

This session will address mBC policy gaps from around the world, patient advocacy initiatives and highlight examples from Asia on how the patient journey can be improved.

**Session type: Discussion panel**

**Number (code): SP14**

Initiatives to Support the Patient Journey

Track 4 – Maximizing quality of life and death.  
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Disclosure of interest: None declared



**Sponsored session**

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