

The Role of Civil Society in the Implementation of the Global Breast Cancer Initiative (GBCI) Framework: Takeaways from Southeast Asia

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Abstract

Background: In 2021, the World Health Organization (WHO) launched the Global Breast Cancer Initiative (GBCI) with the aim of strategically guiding and coordinating efforts to reduce breast cancer mortality in low- and middle-income countries (LMICs). At the country level, GBCI requires adaptation to local contexts based on a systematic assessment of barriers faced by breast cancer patients and the health system's capacity. This requires engaging stakeholders with civil society organizations being key. **Method:** During the 7th Southeast Asia Breast Cancer Symposium (SEABCS) held in Hue, Vietnam, breast cancer clinicians, policy makers, patients, advocates, and caregivers were invited to participate in a workshop to discuss the role civil society organizations will play in the implementation of GBCI. The workshop objective was to identify the needs of CSOs to effectively support the domestic implementation of GBCI principles and strategies. **Result:** Twenty-two people registered for the workshop, with eight civil society organizations represented by one or more members. Participants were assigned to three groups and were asked to describe; (a) the ways in which civil society could use the GBCI framework document, advocate for its implementation at the country level, and support the implementation of recommended interventions; and (b) what would be needed for civil society to use, advocate for, or implement GBCI. **Conclusion:** This report outlines the main discussion points, the roles that civil society can play in countries' implementation efforts, and the resources needed so they can efficiently support their governments in their implementation strategy. By including civil society as a key element of breast cancer control, countries in the region and beyond can accelerate the domestic implementation of the GBCI principles and strategies, making significant progress in breast cancer control and improving the lives of those affected by the disease.

Keywords: breast cancer- global breast cancer initiative- civil society- country plans- implementation

Asian Pac J Cancer Prev, 25 (7), 2561-2565

Introduction

Global Breast Cancer Initiative (GBCI)

In 2021, the World Health Organization (WHO) launched GBCI with the aim of strategically guiding and coordinating efforts to reduce breast cancer mortality in low-and middle-income countries (LMICs) [1]. The Initiative offers evidence-based recommendations for a phased implementation of interventions targeting improvements in early detection, diagnosis, treatment, and supportive services.

GBCI's framework was created using data from countries reporting reductions in breast cancer mortality over the past decade [2]. These countries shared a common approach of implementing a combination of strategies at the population level: early detection, timely diagnosis, and effective multimodality treatments, which collectively and

synergistically contributed to the decrease in mortality.

Reflecting on these strategies, GBCI developed three pillars and three evidence-based key performance indicators (KPIs) designed to pinpoint existing system gaps and facilitate targeted interventions for enhanced breast cancer care delivery: >60% of invasive cancers are stage I or II at diagnosis; diagnostic evaluation, imaging, tissue sampling and pathology within 60 days of presenting with symptoms; and >80% of breast cancers undergo multimodality treatment without abandonment [3]. These three pillars are interdependent as each component relies on the others implemented simultaneously to achieve meaningful reductions in breast cancer mortality.

Through GBCI, the WHO aims to provide guidance to governments on ways to strengthen systems for detecting, diagnosing, and treating breast cancer to achieve the KPI's [3]. GBCI's framework requires adaptation to the local

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context based on a systematic assessment of common barriers faced by breast cancer patients and the health system's capacity to incorporate changes to overcome those barriers. These adaptations to local contexts require engaging domestic stakeholders with civil society organizations being key.

Civil society and GBCI

Civil society refers to the community of citizens and organizations outside of government and business sectors who come together to pursue common interests, promote social change, and advance various causes. It encompasses a wide range of groups, including non-governmental organizations (NGOs), community-based organizations (CBOs), advocacy groups, grassroots movements, religious institutions, charitable organizations, and volunteer associations.

Civil society organizations (CSOs) have been a powerful force for advancing breast cancer control, playing critical roles in providing support, raising awareness, reducing stigma, public education, and fundraising. They also influence policy and impact national cancer research agendas by bringing public concerns about cancer to decision makers and the medical community [4].

In most LMICs, CSOs play vital roles in educating communities, complementing government efforts, delivering services, and advocating for policies that promote equitable access to cancer prevention, treatment, and support. They are trusted and have in-depth knowledge of communities' needs, making them key stakeholders of GBCI along governments, healthcare professionals, and communities [5–8].

Southeast Asia Breast Cancer Symposium (SEABCS)

Since 2016, SEABCS has attracted global and regional experts in breast cancer including clinicians, policy makers, patients, advocates, and caregivers. Representing more than 22 countries [9], these individuals and organizations gather annually to share the latest in breast cancer. The symposium promotes holistic improvements in capacity building around breast cancer, innovations in treatment, supportive care, and patient advocacy, and has become a catalyst behind the creation of a regional-based coalition for women's cancers.

The workshop objective was to identify the needs of CSOs to effectively support the domestic implementation of GBCI principles and strategies. This report outlines main discussion points, and roles civil society can play in implementation efforts. We recognize what we present is limited to SEABCS participants in Hue, Vietnam, August 2023. References are included when appropriate, although this is not intended to be a comprehensive review of breast cancer control efforts in the region.

Materials and Methods

All SEABCS participants were invited to a workshop to discuss GBCI's implementation framework among civil society in Southeast Asia. Twenty-two people registered. Eight civil society organizations were represented by one or more members (iCanserve, Philippines; Indonesian

Breast Cancer Foundation, Indonesia; Bright Future Foundation, Vietnam; Kien Cuong Breast Cancer Club, Vietnam; Schwe Yaung Hnin Si, Myanmar; Global Focus on Cancer, USA; City Cancer Challenge Foundation, Switzerland; ABC Global Alliance, Portugal). In attendance were also two independent patient advocates, seven public health professionals, and representatives of the International Agency for Cancer Research, IARC, Vietnam National Cancer Institute, and Vietnam National Cancer Hospital.

Participants were assigned to three moderated groups and asked to describe; (a) how civil society could use the GBCI framework document, advocate for its implementation at the country level, and support the implementation of GBCI's recommended interventions; and (b) what would civil society need to use, advocate for, or implement GBCI. We applied implementation facilitation techniques as described elsewhere [10]. Answers and notes were collected by moderators on whiteboards, and the information collated and summarized in this report.

Results

The involvement of NGOs and patient organizations is critical to ensure successful implementation of the GBCI framework at the country level. Table 1 summarizes participant responses regarding how civil society could utilize GBCI's implementation framework.

Participants reported the technical package could be used in three main areas: to craft evidence-based educational messages, develop capacity building programs for healthcare providers, and to design organizational objectives and measures of impact. It was noted that in doing so, organizations would enhance their credibility with policy makers, ministries of health, and the public.

Likewise, participants voiced that CSOs could use the framework as a valuable resource/tool to advance advocacy efforts. GBCI provides a comprehensive roadmap for breast cancer control, outlining key principles, strategies, and targets. CSOs can employ these to advocate for the adoption and implementation of evidence-based breast cancer policies at the regional, national, and/or global levels. They believe that referencing the GBCI framework could emphasize the importance of aligning policy efforts with international best practices and recommendations, leading to more robust and effective breast cancer control strategies.

Workshop discussion suggested ways CSOs can support and accelerate the implementation of GBCI's recommended interventions. CSOs can collaborate with healthcare providers, governments, and other stakeholders to reduce barriers to healthcare access, work to improve access to breast cancer early detection, diagnosis, and treatment services for all individuals, including those in marginalized or underserved communities. Patient organizations often provide vital services to breast cancer patients, survivors, and their families. This includes emotional support, counseling, education, and information about available resources and treatment options.

CSOs can play important roles in building capacity

Table 1. How Can Civil Society

Use GBCI's implementation framework?	Advocate for GBCI's implementation framework?	Support the implementation or directly implement GBCI's framework?
Education and awareness: - Educate patients. - Improve communication skills for survivors and patient advocates. - Develop talking points for public awareness and education. Capacity building: - Train health care providers. Improve organizational capacity: - Set organization-wide objectives and KPIs. - Measure organization or program results. - Develop a roadmap for breast cancer control. - Develop fundraising messages and writing grants.	Organizational capacity and planning: - Develop advocacy plans and implement evidence-based advocacy. Communication: - Develop advocacy messages targeted at national level policy makers. - Develop communication plans addressed to policy makers, civil society, or healthcare system. - Reach out to influencers.	Education and awareness: - Implement public awareness and education about breast cancer. Capacity building - Implement interventions for healthcare providers at different levels of the healthcare system. - Develop educational toolkits and training materials. Reduce barriers to access cancer care: - Guide patients across the cancer continuum to complete treatment and improve outcomes. - Improve treatment adherence. - Provide different types of supportive care.

for healthcare professionals and community workers involved in breast cancer care. Via training programs and workshops, they can improve the quality of breast cancer services at various levels of the healthcare system. Additionally, CSOs can fundraise to support research, awareness, and support programs, accelerating the implementation of national breast cancer strategies.

Programmatic requirements, financial needs, and expertise for the planning and implementation of GBCI are significant for most low-resourced economies. Although most countries are committed to progress, each setting has unique levels of expertise, human capital, and financial resources which limit the speed at which they can implement breast cancer control interventions.

Table 2 presents the anticipated needs CSOs participating in the meeting will require to effectively support evidence-based interventions. As shown, these are numerous yet crucial for maintaining civil society support.

Discussion

The GBCI framework stresses raising public awareness about breast cancer risk factors, prevention, and early detection. CSOs can utilize the framework to develop evidence-based educational messages, resources, and public awareness campaigns. By disseminating framework information, they can empower individuals to better understand breast cancer, promote early detection, and

seek timely medical attention. This approach has been implemented for other cancers. UICC's cervical cancer resource page is an example of how a CSO coalition has created and shared infographics, videos, documents and links to support the cervical cancer elimination initiative [11].

GBCI emphasizes the significance of data collection, monitoring, and evaluation in breast cancer control. By leveraging data and research findings presented in the framework, advocacy organizations can make evidence-based arguments, highlight disparities, and identify areas of improvement in care and support services. HIV advocacy is the clearest example of how the collection, analyses, and interpretation of data can be used to develop resources describing the disease landscape in communities and help stakeholders understand successes and gaps in prevention and care.

Finally, CSOs play a crucial role in the delivery of cancer services, particularly in LMICs, and therefore are critical to the implementation of GBCI at the country level. Their involvement can significantly contribute to the success of national breast cancer strategies and the achievement of GBCI's regional targets. Concrete CSO examples in achieving the targets are: (a) implementing community education and awareness, resulting in increased knowledge about breast cancer symptoms, leading to earlier detection and treatment, aligning with GBCI targets to reduce mortality through early diagnosis. (b) Providing

Table 2. Resources that Civil Society Needs

Promote the use of GBCI's framework.	Advocate for the domestic implementation of the GBCI principles and strategies.	Implement GBCI's principles and strategies in country.
Human resources: - Patient experts and cancer advocates. Communication: - Knowledge on how to develop targeted messages to address the gaps assessed from the baseline needs in specific communities. - Training on public speaking and how to exert influence. - Adapt messages to literacy levels, culture, and native languages. - Visuals and multimedia presentations. - Story-telling skills. - Develop dissemination strategies for GBCI's messages. Partnerships: - Develop collaborations with informal leaders in communities. Tools: - Assess the baseline needs in each community.	Human resources: - Communication experts. - Public champions. - Stakeholder maps. - Materials to educate policymakers. - Develop and disseminate best practices and stories of success. Partnerships: - Engagement and support from WHO's country offices. Funding: - Public funding and private sponsors.	Partnerships: - Cross collaborations, specifically from national cancer institutions. - Government support (not exclusively monetary). Implementation tools: - Build capacity for program implementation, data collection and analysis. - Translated materials to local languages. - Digital, interactive and education tools. - Data analysis tools. Funding: - Resources for implementing navigation.

screening and diagnostic services to complement national efforts and reach underserved populations at low-or no-cost, directly contributing to GBCI's target of improving early detection rates. (c) Providing support or navigation services, ensuring continuous care, resulting in improved treatment adherence and quality of life, aligning with GBCI's KPI of 80% of patients completing treatment. Or (d) healthcare provider training on breast cancer early detection to improve skills and knowledge, supporting GBCI's objective to timely detection and diagnosis.

Collaboration among NGOs, patient organizations, government agencies, healthcare institutions, and international organizations is essential for a coordinated and comprehensive approach to breast cancer control. Working together, they can leverage each other's strengths and resources to achieve common goals [4]. The Association of European Cancer Leagues is an example of effective coalition building [12], and although less frequent, we see similar initiatives in LMICs. For example, in Rwanda, CSOs and government have joined forces to accelerate cancer care for women [8].

There is significant expertise among CSOs in Southeast Asia that if properly harnessed, coordinated, and shared, could help plan, catalyze, and accelerate the implementation of GBCI's recommended actions at national levels. One efficient solution to build the needed capacity could involve centralizing and sharing strategies common to all settings. This approach would relieve countries of these tasks and their associated expenses. A few examples of collaborative activities could be situational analysis, development of curricula and materials for training of health care professionals, data management systems, monitoring and evaluation platforms, proposal development, and resource mobilization guidance. CSOs involved in cancer control activities in Southeast Asia may consider building regional coalitions or knowledge hubs to engage more effectively with Governments, or use existing resources via organizations like UICC [13], City Cancer Challenge Foundation [14], or WHO.

Overall, the involvement of NGOs and patient organizations is critical to ensuring the successful implementation of the GBCI framework within countries. Their efforts can lead to improved breast cancer outcomes, increased awareness, and better access to care, ultimately contributing to the achievement of GBCI's set targets in their regions.

Call to action

Promoting domestic implementation of the principles and strategies set out in the WHO's GBCI requires a multi-faceted and multi-sectoral approach. In addition to ensuring domestic action plans are integrated into national cancer policies, further objectives to consider are advocating for increased funding and resources for breast cancer services and research, including securing government budget allocations and encouraging private sector contributions.

Governments will need to build strong partnerships with NGOs, patient organizations, healthcare institutions, research centers, and international agencies to coordinate expertise and resources to effectively address breast

cancer across all levels. The support and empowerment of CSOs to actively participate in policymaking, planning, and implementation processes will be key. Their unique perspectives and experiences can shape more patient-centered and comprehensive breast cancer strategies.

By including civil society as a key element of breast cancer control, countries in the region and beyond can accelerate the domestic implementation of the GBCI principles and strategies, making significant progress in breast cancer control and ultimately improving the lives of those affected by the disease. SEABCS Steering Committee is committed to providing a capacity-building platform for regional civil society to support the development and implementation of national breast cancer strategies. Global policy agencies like WHO, large research institutions, and cancer centers should also support similar initiatives.

Author Contribution Statement

Design of the workshop (AC, CT, KK, KM); Implementation (AC, CT, PB, AP); Preparation of the manuscript and review (All).

Acknowledgements

General

We would like to acknowledge and thank the organizers and participants of SEABCS 2023 for their participation, insights and support.

Approval

All participants were conference registrants. Through registration, attendees consented to having their photo/likeness/recordings used at the discretion of conference organizers. No personal data or individual data is presented in this report.

Ethical Declaration

The work did not require ethical approval since the project involved only anonymized opinions collected with informed consent.

Data availability

Images of the whiteboard exercise are available upon request.

Disclaimer

Where authors are identified as personnel of the International Agency for Research on Cancer/WHO, the authors alone are responsible for the views expressed in this article and they do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer/WHO.

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