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The Breast Health Global Initiative

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PLANNING:
PLANNING COMPREHENSIVE BREAST CANCER PROGRAMS: CALL TO ACTION

About this Knowledge Summary (KS):

This summary covers planning for breast cancer programs, including long-term planning. It provides an introduction to two important concepts: knowledge summaries and resource-stratified pathways.

KEY POLICY SUMMARY:

Breast cancer control programs

- National breast cancer control programs can be developed and implemented at all resource levels.
- Successful breast cancer programs offer women with breast cancer the best possible outcomes while effectively using available resources.

Policy planning

- Effective cancer control programs require comprehensive cancer control plans.
- A fundamental shift in cancer program planning is needed – from short-term, vertically funded programs, to long-term programs integrated into the overall health system.
- Comprehensive national cancer plans can provide the framework for breast cancer program development, but should be adapted to meet local needs and available resources and should be integrated into existing services along the continuum of care.
- Data on existing health system capacity can identify areas for program improvement.

Breast cancer control programs

- National breast cancer control programs can be developed and implemented at all resource levels.
- Successful breast cancer programs offer women with breast cancer the best possible outcomes while effectively using available resources.

Knowledge Summaries (KS) for breast cancer control

- KS can be used in developing or implementing national cancer control plans to inform stakeholders about key breast cancer policy issues.
- KS can ensure that key information needed to understand resource needs along the continuum of care (prevention through treatment and palliation) are shared among stakeholders and decision makers.
- KS provide resource-stratified pathways and can facilitate decision making by policy makers, healthcare administrators and advocates engaged in implementing breast cancer control programs at various resource levels.

Resource-stratified pathways across the continuum of care

- Program design and improvements should be based on identified needs and barriers, outcome goals and available resources.
- Breast cancer programs should follow a defined resource-stratified pathway to ensure coordinated incremental program improvements across the continuum of care (see Table 1).

INTRODUCTION & THE CHALLENGE

Breast cancer is the most prevalent cancer in women worldwide, affecting over 1.5 million women each year. Low- and middle-income countries (LMICs) bear an increasing and disproportionate share of the disease burden. Women in low-resource settings commonly present to a healthcare facility with advanced breast cancer and have a poor prognosis (as low as 15% overall 5-year survival in some regions) and poor quality of life. In high-income countries (HICs), breast cancer control programs have successfully reduced the percentage of women who present to a healthcare facility with advanced breast cancer. Most women diagnosed with early stage disease (I and II) have a good prognosis with overall 5-year survival rates of 80-90%. Differences in outcomes between LMICs and HICs have been attributed to effective awareness and screening programs, timely access to appropriate treatment and reduced cultural barriers to care in HICs. There are also differences in breast cancer supportive care services, such as survivor networks and access to pain management. The success of breast cancer control programs in HICs (and some LMICs) demonstrates that improvements in early diagnosis, effective treatment and supportive care are achievable. The challenge is to make breast cancer control planning and program implementation a health priority

In 2005, the World Health Organization (WHO) passed a landmark resolution on cancer prevention and control, recognizing that cancers could be prevented or detected early in their development, treated and cured; and that all countries can design and implement effective cancer control plans that allow for a balanced, efficient and equitable use of resources (see Table 1).

POLICY ACTION
OVERVIEW

Preplanning

- Assess if a new breast cancer program is needed (e.g., program is nonexistent, outdated, ineffective, not resource-appropriate or new services will be integrated).
- If needed, who will lead the process?

Planning Step 1: Where are we now? (Investigate and assess)

- Assess the breast cancer disease burden and the capacity of the health system to respond to breast cancer cases (human resources, gaps in services, barriers, etc.).

Planning Step 2: Where do we want to be? (Set goals and objectives)

- Identify and know your target population
- Identify and engage stakeholders
- Identify goals, priorities and strategies based on effective utilization of existing resources, and development and implementation of new programs in a stepwise fashion along a resource-stratified pathway.
- Assess feasibility of interventions

Planning Step 3: How do we get there? (Implement and evaluate)

- Follow a resource-stratified pathway for prevention, early detection, diagnosis, treatment and palliative care.
- Engage appropriate resources, decision-makers and staff
- Use the pathways to ensure that improvements in breast cancer control take place in parallel along the continuum of care.
- Match resource-level investments along the continuum of care.
- Monitor and evaluate

WHAT WE KNOW

Breast cancer care is most successful when prevention, early detection, diagnosis, treatment and palliation are integrated and synchronously developed. Early detection does not benefit a woman unless she has timely access to appropriate treatment. A patient-centered treatment plan cannot be generated without an accurate pathologic diagnosis, and a patient's preferences and barriers to treatment adherence are identified and addressed. Comprehensive breast cancer care requires an effective health system with trained community health personnel, nurses, psychologists, therapists and other professionals.

Burden of breast cancer disease

Breast cancer is the leading cause of cancer death among women, accounting for 23% of all cancer cases and 14% of cancer deaths. Between 1980 and 2010, the annual number of breast cancer cases worldwide increased more than two and a half times, from 641,000 to 1.6 million. By 2030, the total number of breast cancer cases per year is expected to reach 2.4 million, with an increasing proportion occurring in LMICs. Currently, more than half of new breast cancer diagnoses and 62% of cancer deaths occur in LMICs, the majority of these diagnoses are late stage or advanced disease.

Financial burden and economic impact of breast cancer

Patients, families and societies all experience the financial burden and economic impact of breast cancer. In addition to the direct medical costs (which increase with late stage diagnosis), there are costs associated with transportation, childcare and housing as well as the hidden costs of lost productivity due to morbidity or premature death.

Cost-effectiveness analyses on breast cancer care interventions are available, but vary widely and the transferability of these evaluations across countries is difficult, as clinical practice patterns, health systems and cultural and social practices differ. Nevertheless, reviewing cost-effectiveness studies from other countries may help inform breast cancer control planning discussions and resource allocations.

Prioritizing breast cancer programs in the health system

Health systems are faced with balancing four competing principles: scope of services, equity in access to services, quality of care and cost containment. Using a scope of service approach requires health systems to assess and coordinate available public and private services. Equity in access to services requires health systems to ensure that women in rural settings and of lower socioeconomic status have access to breast services.

Quality of care requires routine evaluations for safety, effectiveness, patient-centeredness, timeliness, efficiency and equity. It also requires an ongoing evaluation of the burden of disease (e.g., increase incidence or change in late stage versus early stage presentation) and the potential for dramatic improvement in patient care such as the introduction of new targeted therapies or psychosocial services.

Each country, and each region within a country, will have a different set of health priorities. Breast cancer programs should be implemented based on available resources, and the projected benefit (e.g., reduction in late stage disease presentation, improved access to care), using a resource-stratified pathway that will allow programs to advance in a coordinated and stepwise fashion across the continuum of care. Process metrics should be built into all project plans to identify and measure program strengths and weakness. Framing programs using these four competing principles can help prioritize interventions.

Translation of research into health policy and practice

Effective translation of research into health care policy and practice requires analysis of the existing health system and an understanding of the barriers to implementation of evidenced-based practices. Qualitative research (focus groups and interviews) can help identify existing barriers, for example identifying why some women in the target population do not take advantage of breast health awareness or screening services, while implementation science provides a method by which researchers can assess new interventions or understand a causal relationship between an intervention and its impact. Implementation science is the study of methods to promote the effective integration of research findings and evidence into policy and practice and seeks to understand barriers to implementation as well as the behavior of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption and implementation of evidence-based interventions. This type of research is essential to understanding and effectively addressing potential problems such as sub-optimal participation in screening, poor referral rates or high loss-to-follow up.

Historically, breast cancer programs have been integrated using a "vertical" or "horizontal" approach. In a vertical approach, programs are introduced and run separately from other existing health programs; whereas in a horizontal approach, a new program is integrated into existing health programs. Though each approach has advantages and disadvantages, the emphasis on implementation should be on integration, for example adding in prevention strategies into existing women's health services but also establishing new cancer treatment services, utilizing vertical-horizontal synergies or a "diagonal approach". Factors that impact the implementation of health programs include: the behavior of healthcare professions and other stakeholders, leadership of the reform, political will and strategies, relationship between advocates and policymakers, ownership of the program, timing of the proposed intervention and sustained financial resources and commitment.

These factors should be considered as new programs are proposed. Additionally, partnerships between researchers, health professionals, advocates and policymakers must be developed and maintained to ensure programs function effectively and policies are evidence based rather than politically motivated.

National policies and local implications

Healthcare delivery at the local level (micropolicy) is impacted by national policies (macropolicy), particularly for healthcare resource allocations and financing issues. In low-resource settings, high user fees imposed by national policies may negatively impact local healthcare utilization and place an unsustainable financial burden on patients and their families. National policies must balance cost containment and the financial burden of care to patients and health systems to ensure women of all socioeconomic statuses have equitable access to care. This requires healthcare policymakers and administrators to have a detailed understanding of disease management and local socioeconomic factors that contribute to disparities in access to care.

Human resources

Human resource limitations (volume and training) pose a significant challenge to accessing care, particularly in low-resource settings. Health professionals often encounter unfavorable work environments, heavy workloads and low remuneration, among other concerns, which are compounded by projected shortages of nurses and physicians at all resource levels. Gaps in and barriers to breast cancer care exist at all resource levels and income settings, and discrepancies in care may worsen as greater demand is placed on the health system (see Improving Access to Care module).

PLANNING STEP 1:
WHERE ARE WE NOW?

POLICY ACTION:
INVESTIGATE AND ASSESS

Assess the breast cancer burden

- Cancer registries can provide data on breast cancer incidence and reflect the demographics at risk, as well as capture disease stage at presentation.

- Hospital-based records or registries can help establish the local disease burden if population-based registry data are not available.

- Consider regional variations in the incidence of breast cancer.

Assess existing cancer control plans and activities

- Review current breast cancer control programs and/or perform a country-wide situational analysis of breast cancer care.

- Assess what is available, where it is available, how it is being used and the quality and effectiveness of the service.

- Assess human resource capacity, breast cancer awareness and early detection programs, availability of diagnostic and treatment modalities and supportive care services.

- Assess barriers to program implementation and utilization of services.

- Establish a baseline reference for future program development and evaluations.

Available country self-assessment tools

- WHO One Stop Portal for NCD Prevention and Control Tools **www.who.int/nmh/ncd-tools/en/**

- WHO National cancer control programs **www.who.int/cancer/nccp/en/**

- WHO Cancer control: knowledge into action **www.who.int/cancer/modules/en/**

- The National Cancer Institute: Human Resource Assessment **http://rrp.cancer.gov/programsResources/human_resources_needed.htm**

- The International Cancer Control Partnership portal **www.iccp-portal.org**

WHAT WORKS

Collaboration: multi-stakeholder and multi-sector involvement

Collaboration among all health sectors and stakeholders is essential to advancing healthcare delivery. In many countries, the government shapes healthcare through legislative policies, budget allocation, training of health professionals, promoting research agendas and maintaining oversight. Achieving governmental support for healthcare issues requires collaboration between committed health experts, advocates and policymakers to generate the necessary political will to support change. Advocacy efforts by breast cancer patients and survivors, their families and friends, health professionals, health industry and the media have all impacted the promotion of breast cancer care in HICs. Greater impact can be achieved when efforts are coordinated to guide policymakers toward effective and desirable change.

Private institutions and non-governmental organizations (NGOs), in the field of cancer as well as reproductive and women's health, should be considered as potential partners and contributors to healthcare delivery in all resource settings. NGOs provide a variety of services including research support, financing programs, communicating key messages and educating the public, strengthening existing collaborations, providing fellowship training grants, sponsoring workshops and promoting government and policy action. Academic institutions can also serve as valuable partners, using a shared partner model known as twinning, wherein two or more global institutions share experience, expertise and resources toward a common goal.

NGO participation in health programs should be coordinated with the governmental health agency and monitored for the effects on health system infrastructure and equitable delivery of care. The activities of the non-governmental and private sector may limit health system efficiencies and effective resource-stratified planning if these efforts are not synchronized with health policy efforts.

Survivors as stakeholders and advocates for patient-centered care

Breast cancer survivors can help ensure that programs are locally relevant, can inform key quality of care and patient-centered care issues and can enhance the sustainability of programs. Patient-centered care (i.e., the use of individual patient values and preferences to guide cancer care decision making) has been shown in HICs and LMICs to be effective and does improve patient decision-making and satisfaction with care.

Health systems design – centralized services

Health systems must be designed to optimize services and coordinate care amongst primary care centers (which are the most frequent first contact for breast cancer patients), specialist services (e.g., biopsy, cytology, pathology review), treatment services (e.g., surgery, radiation therapy, systemic therapy) and palliative care services. The relationship between volume and outcome should be considered, particularly for invasive procedures or advanced modalities (i.e., higher volume often results in better outcomes). However, centralization of breast cancer services may also increase barriers to care, particularly for women in rural communities who already have limited access to early detection and primary care. Standardization of protocols, a transparent system of referrals, multidisciplinary team approach, quality assurance measures (i.e., process metrics), patient navigation and a patient-centered approach to care are all critical features of an effective health system.

Data collection and cancer registries

Identifying the scope of the burden of breast cancer can be difficult in regions without cancer registries, precise demographic data or documented causes of death. In such situations, a review of hospital-based records or registries can provide an estimate of the breast cancer incidence. Data on tumor stage at initial diagnosis should be collected as part of cancer registries, as this data can inform program direction. For example, if most breast cancers are being diagnosed at an advanced stage, assessing and improving efforts to increase early detection would be warranted. Establishing and administering a cancer registry requires participation and coordination of governmental agencies, health facilities, health professionals and other stakeholders. Countries developing new registries can benefit from lessons learned by those with established registries and should consider contacting relevant countries.

PLANNING STEP 2:
WHERE DO WE WANT TO BE?

POLICY ACTION:
IDENTIFY OBJECTIVES AND PRIORITIES

Know your service and target population

- Identify and engage stakeholders in breast cancer program planning, including identifying target populations for program outreach. Relevant stakeholders are policymakers, health professionals, administrators, donors, advocates (including patients and breast cancer survivors) and the general population.
- Identify high-risk groups using breast cancer incidence and risk data.
- Identify underserved groups including the rural and urban poor and those with limited health literacy.

Identify gaps and barriers

- Review existing information on health system barriers and patient barriers to care in the target population. Identify additional barriers and gaps in service for breast cancer care.
  - Patient barriers may include a lack of knowledge or misconceptions about risk factors, signs and symptoms and treatment of breast cancer.
  - Health system barriers may include insufficient numbers of appropriately trained healthcare workers, limited access to screening/treatment facilities, inadequate supplies of necessary drugs and delays in treatment.

Set achievable objectives

- Use evidence-based strategies that are feasible, cost-effective and based on local needs, interests, strengths and resources.
- Breast cancer outcomes are affected by how effectively a health system provides early diagnosis, prompt and equitable access to optimum care and coordination of care across the continuum of care.

Determine feasibility of new programs before widespread implementation

- Phased implementation or pilot projects may help ensure program feasibility prior to population-wide implementation.
- Follow a resource-stratified pathway for program development that identifies available resources across the continuum of care.

HOW DO WE GET THERE?

The resource-stratified pathway

Countries vary in wealth, culture, and societal preferences in regard to healthcare; within countries there can be vast differences in capacity and in cancer burden, most notably between urban and rural areas. Evidence-based resource-neutral guidelines from HICs cannot always be easily translated into practice in limited-resource settings. Resource-stratification is a process whereby standard healthcare interventions are grouped by attributes that affect their feasibility in different settings, including costs, level of complexity and demands on the healthcare system.

The Breast Health Global Initiative (BHGI) applied an evidence-based consensus panel process to build a framework defining resource prioritization pathways for early detection, diagnosis, treatment, and delivery systems at four levels of available resources: basic, limited, enhanced, and maximal. Resource-stratified guidelines provide an alternative framework and allow ministries of health to identify deficits in resource allocations and facilitate breast cancer control planning. Resource-stratified breast cancer guidelines, such as those developed by the BHGI, have improved health system coordination and are now being applied to other cancer programs.

Knowledge summaries for breast cancer control

The KS for breast cancer control provide resource-stratified pathways to facilitate decision making by policy makers, healthcare administrators and advocates engaged in implementing breast cancer control programs at various resource levels. The KS emphasize coordinated, incremental program improvements across the continuum of care to achieve the best possible outcomes at each resource level. The sixteen KS for breast cancer control address planning, prevention, early detection, diagnosis, treatment, palliative care and policy and advocacy.

Guideline development

Developing shared standards of clinical practice that consider available resources can help ensure that patients receive the best possible care. To that end, the Union for International Cancer Control (UICC) has developed the International Cancer Control Partnership (ICCP) portal (www.iccp-portal.org) to assist countries in implementation efforts by compiling resources, toolkits and frameworks in one location (see Appendix).

Research and data

Health ministries in LMICs often have limited data available to determine how breast cancer can best be managed in a country or region. Research collaborations and standardized data collection are required to advance breast cancer program planning, and are increasingly becoming priorities in LMICs. In the African Union, 20 countries now have cancer registries; and there are over 700 LMIC studies published on breast cancer awareness.

Clinical research in LMICs is expanding to include disease risk factors, treatment efficacy and patient outcomes, breast cancer program implementation and healthcare policy. Implementation science and qualitative research is being used to facilitate breast cancer care delivery by assessing the social, psychological and system barriers to care. Situational analyses can provide comprehensive contextual reviews of an existing health system or health program, and needs assessments can identify gaps between a current situation and a targeted outcome and identify areas needing intervention. Collaborations in basic science research generally require more intensive resources and expertise, but can provide important information about pathophysiology (i.e., cellular markers) of breast cancer in specific populations.

Data collection should be tailored to inform policy decisions. For example, an analysis of screening mammography capacity requires identification of the number of functioning imaging units, where they are located, whether and how they are being used, if the generated images are of adequate quality, whether involved personnel are utilizing best practices and whether ongoing resources are available to sustain a screening program. Published examples of successful data collection programs can inform other national efforts such as in the case of Brazil, where a national information system was developed to capture and organize these data.

Quality assurance programs

Program monitoring can be conducted using assessment tools to capture outcome indicators or various metrics to measure quality, cost, access, patient experience and more. Quality assurance is an essential part of any health intervention; incorrect pathology assessments can result in inappropriate treatment and poor outcomes. False-positive screening mammography results can lead to over-diagnosis and unnecessary biopsies, imaging studies or treatments. Similarly, improperly performed surgical procedures can increase the loco-regional recurrence rate. Quality care results in better outcomes, improved patient satisfaction and increased community trust, which are all important to successful cancer control.

PLANNING STEP 3:
HOW DO WE GET THERE?

POLICY ACTION:
IMPLEMENT AND EVALUATE

Establish financial program support

- Consider government funding, resources generated by NGOs and advocacy efforts and donor support. Multi-sectored involvement should include public-private partnerships, twinning and research collaborations.
- Recognize that long-range planning can shift the care expenditures from advanced disease and palliation to early detection and prevention.

Launch, disseminate and implement

- Implementation should focus on proven methods of translating healthcare policies into clinical practice, should consider local political and sociocultural factors and involve all stakeholders.
- Disseminate program plans (goals, objectives and best practices) to health system stakeholders, professional societies and the public to ensure synchronized program implementation and messaging.

Monitor and evaluate

- Establish assessment, process and quality metrics and outcome measures at the start of a program, with the understanding that it may take 2-3 years or more for data to show valid outcomes.

CONCLUSION

Successful national cancer control programs require thoughtful planning that involves all stakeholders, includes situational analysis and needs assessments, utilizes population-based data on breast cancer incidence and tumor stage at presentation and considers existing health system capacity. An evidence-based resource-stratified pathway can facilitate the process of breast cancer control program design and implementation

Comprehensive breast cancer control planning is a long-term process that requires acknowledgement that changes in population-based outcomes can take years to realize. Pilot projects, research studies and quality assurance programs that use short- and long-term process metrics can help inform future program direction. Clinicians and policymakers should remain optimistic that with effective, collaborative breast cancer control planning and the implementation of effective tools in early detection, diagnosis and treatment, they can contribute to the improved health care of the millions of women.

Table 1. Primary actions for national cancer control programs, according to level of resources (WHO 2002)

Component	All countries	Scenario A: Low level of resources	Scenario B: Medium level of resources	Scenario C: High level of resources
National cancer control program	• Develop a national cancer control program to ensure effective, efficient and equitable use of existing resources • Establish a core surveillance mechanism to monitor and evaluate outcomes as well as processes • Develop education and continuous training for health care workers	• Consider the implementation of one or two key priorities in a demonstration area with a stepwise approach • Consider palliative care as an entry point to a more comprehensive approach • Use appropriate technologies that are effective and sustainable in this type of setting	• When initiating or formulating a cancer control program, consider implementation of a comprehensive approach in a demonstration area using a stepwise methodology • Use appropriate technologies that are effective and sustainable in this type of setting	• Full, nationwide implementation of evidence-based strategies guaranteeing effectiveness, efficiency, and accessibility • Implement a comprehensive surveillance system, tracking all program components and results • Provide support for less affluent countries
Prevention	• Implement integrated health promotion and prevention strategies for non-communicable disease that include legislative/regulatory and environmental measures as well as education for the general public, targeted communities and individuals • Control tobacco use, and address alcohol use, unhealthy diet, physical activity and sexual reproductive factors • Promote policy to minimize occupational-related cancers and known environmental carcinogens • Promote avoidance of unnecessary exposure to sunlight in high-risk populations	• Focus on areas where there are great needs and potential for success • Ensure that priority prevention strategies are targeted to those groups that are influential and can spearhead the process (e.g., policymakers and teachers) • In areas endemic for liver cancer, integrate HBV and other vaccination programs	• Develop integrated clinical preventive services for counseling on risk factors in primary health care settings, schools, and workplaces • Develop model community programs for an integrated approach to prevention of noncommunicable disease	• Strengthen comprehensive evidence-based health promotion and prevention programs and ensure nationwide implementation in collaboration with other sectors • Establish routine monitoring of ultraviolet radiation levels if the risk of skin cancer is high

Table 1. Continued

Component	All countries	Scenario A: Low level of resources	Scenario B: Medium level of resources	Scenario C: High level of resources
Early diagnosis	• Promote early diagnosis through awareness of early signs and symptoms of detectable and curable tumors that have high prevalence in the community, such as breast and cervical cancer • Ensure proper diagnosis and treatment services	• Use low-cost and effective community approaches to promote, in a first phase, early diagnosis of one or two priority detection tumors in a pilot area with relatively good access to diagnosis and treatment	• Use low-cost and effective community approaches to promote early diagnosis of all priority detectable tumors	• Use comprehensive nationwide promotion strategies for early diagnosis of all highly prevalent detectable tumors
Screening	• Implement screening for cancers of the breast and cervix where incidence justifies such action and the necessary resources are available	• If there is already infrastructure for cervical cytology screening, provide high coverage of effective cytology screening for women aged 35 to 40 years once in their lifetime or, if more resources are available, every 10 years for women aged 30 to 60 years	• Provide national coverage cytology screening for cervical cancer at 5 year intervals to women aged 30 to 60 years	• Effective and efficient national screening for cervical cancer (cytology) of women over 30 years old and breast cancer screening (mammography) of women over 50 years of age
Curative therapy	• Ensure accessibility of effective diagnostic and treatment services • Promote national minimum essential standards for disease staging and treatment • Establish management guidelines for treatment services, essential drugs list, and continuous training • Avoid performing curative therapy when cancer is incurable and patients should be offered palliative care instead	• Organize diagnosis and treatment services, giving priority to early detectable tumors	• Organize diagnosis and treatment services, giving priority to early detectable tumors or those with high potential of curabilityrs	• Reinforce the network of comprehensive cancer treatment centers that are active for clinical training and research and give special support to the ones acting as national and international reference centers
Pain relief and palliative care	• Implement comprehensive palliative care that provides pain relief, other symptom control, and psychosocial and spiritual support • Promote national minimum standards for management of pain and palliative care • Ensure availability and accessibility of opioids, especially oral morphine • Provide education and training for carers and public	• Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care in targeted areas and that there is high coverage of patients through services provided mainly by home-based care	• Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care and nationwide there is rising coverage of patients through services provided by primary health care clinics and home-based care	• Ensure that national pain relief and palliative care guidelines are adopted by all levels of care and nationwide there is high coverage of patients through a variety of options, including home-based care

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