

Change Package Toolkit: Improving post-screening follow up and quality of treatment

Purpose: This toolkit is intended to help state teams address disparities in breast cancer mortality by implementing data-driven strategies focused on improving (1) post-screening follow-up and (2) quality of treatment. Gaps can occur both during care and during transitions between phases in the care continuumⁱ -- both should be addressed.

NOTE: This toolkit is meant to offer a comprehensive array of evidence-informed and promising strategies: All listed strategies are not necessarily applicable to all sites.

- **Gaps and barriers identified during Year 1 data collection and mapping should guide the selection of strategies.**
- The change strategies and implementation steps are overlapping, iterative and complementary
- ASTHO expects this to be a dynamic and data-driven, with a mechanism for integrating changes and updates based on lessons learned from ongoing tests of change

Assumptions “Responsibility for care and outcomes is shared among communities, health care systems, clinicians and patients”ⁱⁱ. Based on these assumptions, interventions need to take place at each level. Lessons learned from the Chicagoⁱⁱⁱ effort to reduce disparities in breast cancer mortality are also important to remember:

- *No single entity can fix what is broken*
- *Simply fixing one part of the breast health continuum of care would not be enough*
- *Use quality improvement methodology to address racial disparity in breast cancer mortality across the continuum of care*

Year 1 (2015-2016): State health departments have completed work to strengthen their ability to mobilize data resources more effectively to address disparities in breast cancer and identify modifiable factors that influence follow-up and quality of care at multiple levels of the social-ecological model.

Year 2: Use data collected in Year 1 to identify and implement appropriate strategies for improving follow-up and quality of treatment where they are most needed and feasible. Continue to collect data at regular intervals during implementation to test the intervention steps using rapid cycle tests of change

Table 1: Follow-up: Barriers and Strategies

INFLUENCERS	BARRIER	STRATEGIES	IMPLEMENTATION STEPS:PDSA (examples)
Community	<p>Community and patient beliefs and fears: The literature describes modifiable patient attitudes and beliefs: cancer myths^{iv}; fear of diagnostic tests; lack of knowledge of follow-up and treatment^v; distrust of the health care system; low expectations of medical care^{vi}; denial^{vii}; stigma^{viii}.</p>	<p>Develop and implement a comprehensive clinical-community linkages strategy: A number of promising strategies can be used to address community and patient level barriers. These strategies should be implemented both at the broader community level as well as at the patient level</p>	<ul style="list-style-type: none"> -- With the goal of increasing patient self-advocacy for timely follow-up, implement a patient centered education and empowerment campaign to provide the target population with knowledge regarding screening and standard follow-up procedures so that patients can self-advocate for proper and timely follow-up in the event of abnormal screening results. -- Leverage existing community resources to ensure that outreach, counselling and support can be delivered by race/ethnicity congruent community health workers and outreach workers who are known and trusted in the community and who know their community. -- Collect and report both process and outcome data and report back to community an clinicians to motivate engagement and change
		<p>Implement or expand system-wide patient-navigation strategy to ensure effective and efficient patient-centered transition of care from screening to follow-up and treatment</p>	<ul style="list-style-type: none"> -- Increase the use of Patient Navigators to assist the patient with scheduling and follow-up care -- One-on-one counselling by patient navigators who are responsible for facilitating compliance with follow-up instructions. -- Integrate patient navigators both at the community and the clinical system level to help patients transition between screening and follow-up. -- Embed follow-up protocols in EMR or in hospital protocols
		<p>Identify and reduce physical barriers to timely follow up and continuity of care</p>	<ul style="list-style-type: none"> --Increase research efforts to understand transportation barriers, i.e. driving distance and/or time between patient populations and nearest treatment facilities. -- Implement free or subsidized transportation services determined by the level of accessibility to breast cancer services in terms of geographic distribution and transportation services -- Implement policy and funding strategies to ensure that there are adequate and accessible provider networks for follow-up care --Develop and implement a plan to address patients who are displaced by changes in location or staffing of regional health care facilities

<p>Physician/care team/health-care system</p>		<p>Implement a strategy to provide clinicians with resources and training to ensure proper categorization of abnormal results, and ensure implementation of standardized recall and follow-up protocols</p>	<ul style="list-style-type: none"> -- Implement point of care aids aimed at standardizing interpretation and recall procedures including peer-to-peer communication methods.: ensure these are readily available, user-friendly and accessible to clinicians at point of care -- collaborate with referring providers to encourage proper categorization and recall. -- Implement clear and consistent follow-up protocols/pathways for each category of suspicious screening test results. -- Provide training and mentoring using innovative methods to reach geographically remote practices -- Develop follow-up protocols between PCPs and specialists -- collect and report both process and outcome data and report back to clinicians to motivate engagement and change
<p>Public Health system. Policy</p>	<p>State health official role – payer system and public health system – silos in data exchange standards, measures. Communication barriers</p>	<p>Implement strategies to engage different partnerships to make change</p> <p>Enhanced peer-to-peer and patient communication and tracking systems</p>	<ul style="list-style-type: none"> -- Enhance efficiency of physician-physician communication of abnormal screening results by establishing protocols regarding next-steps and patient notification. -- Implement a system for increasing the effectiveness of patient notification and communication. The goal is to ensure that the message is received and understood in a way that patient is most likely to comply with follow-up. Steps include developing culturally sensitive messages and delivering the messages using best practices, including engaging multidisciplinary teams in the community and clinical setting that include race/ethnicity congruent team members (e.g. community health workers, patient navigators). -- Implement protocols that require both the radiologist’s office (screeener), as well as referring PCP, to communicate results and discuss follow-up with the patient. -- Implement the use of technology through EMR to help physicians track patients with abnormal screening results. -- Develop and implement a method for tracking patients whose addresses change frequently, or who are homeless by collaborating with public health or social security. Consider partnering with payers to provide transient patients who have abnormal screening findings with a “burner” cell phone when they are screened -- Improve partnerships with clinical data sources and establish health information exchange to evaluate implementation barriers and the times between diagnosis and treatment. -- Utilize Regional health information exchanges (HIE) or shared EMR and/or claims data as ways of tracking patient outcomes

Table 2: Quality of Care: Barriers and Strategies

INFLUENCERS	BARRIER	STRATEGIES	IMPLEMENTATION STEPS:PDSA (examples)
Community	Physical barriers, such as geographic location and limited access to transportation have been well documented in the literature (Goodwin et al., 1996), (Farrow, 1996; Harlan et al., 1995; Samet et al., 199X; Nattinger, 1992).	Identify and reduce modifiable contextual barriers to treatment such as transportation and social support	<ul style="list-style-type: none"> --Increase research efforts to understand transportation barriers, i.e. driving distance and/or time to treatment facilities. -- Implement free or subsidized transportation services determined by the level of accessibility to breast cancer services in terms of geographic distribution and transportation services -- Implement policy and funding strategies to ensure that there are adequate and accessible provider networks for follow-up care -- Develop and implement a plan to address patients who are displaced by changes in location or staffing of regional health care facilities
	Lack of social supports influences compliance with treatment, (e.g. more Black and Hispanic patients reported that participation in support groups helped them continue with treatment (Guidry et al., 1997)	Implement strategies to enhance community based support systems	<ul style="list-style-type: none"> -- Identify and collaborate with community based helping and mentoring networks -- Provide space for support groups and other networking and support opportunities, such as group yoga and meditation, cooking classes etc.
	Literature suggests that patients' knowledge, attitudes, and beliefs may affect compliance with treatment (e.g. Ayres et al (1994) found greater compliance was associated with higher scores on the Mental Adjustment to Cancer (MAC) and the Affects Balance Scale	Identify patients who may need additional psychosocial support, and provide support through nurse navigator or clinical social workers	

<p>Physician/care team/health-care system</p>	<p>Physician and care-team level barriers Physician recommendation has been found to be the strongest predictor of patient treatment choice (Siminoff, 1989), and recommendations are influenced by several modifiable factors including perception of patient characteristics, attitude about patient's role in decision making, physician and medical team's communication style, and knowledge of treatment guidelines and novel therapies, attitudes and beliefs about treatment efficacy (GIVIO, 1989 #836),</p> <p>Communication Physicians and their teams relay key information and the delivery and content plays a critical role in patient compliance and healthy behaviors (Fox, 1994); Carter 1982). Adjustment to cancer (Roberts et al, 1994) clinical outcomes and quality of life (Greenfield, 1988)</p>	<p>Implement a system-wide strategy focused on providing clinical teams with tools and resources, mentoring and ongoing training to overcome barriers</p>	<ul style="list-style-type: none"> -- In-service education, training, professional development, tools, mentoring, point-of service aids -- Use performance data to assess progress and impact of strategy -- Establish or expand an existing physician tele-mentoring and teleconsulting program (such as those established as part of Project ECHO) that partners clinicians from established high treatment quality treatment providers with hospitals and cancer clinics in rural or underserved areas to improve the quality of clinical care provided in demonstrated areas of need. -- Provide clear guidelines, tools and resources to enable physicians and clinical teams to use shared-decision making communication methods with patients
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	<p>Adherence to Guidelines Physician compliance with primary and adjuvant treatment guidelines is reported as poor especially among non-academic physicians (Nattinger et al., 1996, Schleifer et al, 1991).</p>		
	<p>Difficulty navigating a complex system and overwhelming treatment and testing schedules in a sometimes fragmented system</p>	<p>-- Establish or expand an existing patient navigation program that assists diagnosed breast cancer patients in seeking and receiving appropriate treatment in a timely manner.</p>	<p>-- Navigation team varies, and is based on organizational structure, community needs, and resources, may include oncology social workers, nurses, physicians, community navigators</p> <p>-- Ongoing patient-centered communication to patients and shared decision making about treatment options, risk of recurrence, side-effects, expected impact on overall quality of life</p> <p>-- Provide increased psychosocial support to patients who need additional psychosocial support (for example lower scores on questionnaires such as the Mental Adjustment to Cancer (MAC) scale may be associated with non-completion of treatment</p>
	<p>Treatment related side effects such as neutropenia, anemia, dehydration, poor kidney function and other abnormal labs frequently present a medical reason for treatment interruption or discontinuation.</p>	<p>Management of side effects: Identify and track quality care outcomes with the goal of reducing treatment related side effects that may interrupt treatment</p>	<p>Examples of quality care measures related to management of side effects include:</p> <ul style="list-style-type: none"> - Treatment related ER use - Treatment related hospital admissions - Interruption of treatment due to medical need (e.g. neutropenia, kidney failure etc.) or other preventable side effects - Interruption of treatment due to patient experience of side effects (nausea management, fatigue)

	Side effects such as nausea, fatigue and discomfort may result in patient non-compliance with treatment		----Work with payers to align reimbursement with quality
Public Health system		Use data to identify and address broad system-level quality of care barriers . Some examples of barriers may include structural and capacity barriers such as limited number of providers, limited treatment services, poor referral networks, access to essential medications. Geographic or socio-cultural gaps in access to multi-disciplinary culturally relevant care teams, patient navigation services. Barriers in inter-system and intra-system communication and data sharing.	<ul style="list-style-type: none"> --Identify and map the distribution of health professionals and diversity of care teams (primary care, specialists, support-staff/care teams, patient navigators). --Identify and map the availability and accessibility of essential and advanced medicines and specialty services (surgical services, pathology services, radiation therapy, chemotherapy, palliative care and supportive care). --Implement policy interventions to reduce structural barriers such as recruitment and training of health professionals, incentivizing providers to locate in areas where gaps are identified, Implement policy interventions designed to facilitate access to essential medicines, including anti-emetic and opioid analgesics. --Identify existing and potential community and health system partnerships, and implement strategies to engage community based stakeholders, survivor groups and advocates in providing formative data and guiding program planning, assisting in program implementation --Work with payers to align reimbursement with quality
		Implement a regional health information exchanges (HIE). Or system level shared EMR as opportunities for tracking patient outcomes	
		Accreditation: Provide resources and support through the development of a white paper to encourage hospitals and	

		<p>cancer clinics to seek accreditation from a reputable accreditation program (e.g., the Commission on Cancer or the National Accreditation Program for Breast Centers).</p>	
		<p>Partner with hospitals and cancer clinics to assess if the quality of breast cancer treatment measures exceed the established benchmarks of quality treatment (e.g., National Quality Forum).</p>	

ⁱ Jane G. Zapka,² Stephen H. Taplin, Leif I. Solberg, and M. Michele Manos. A Framework for Improving the Quality of Cancer Care: The Case of Breast and Cervical Cancer Screening *Cancer Epidemiology, Biomarkers & Prevention* Vol. 12, 4–13, January 2003 Downloaded from cebp.aacrjournals.org on March 25, 2016. © 2003 American Association for Cancer Research

ⁱⁱ *ibid*

ⁱⁱⁱ Ansell, D., Grabler, P., Whitman S., Ferrans, C., Burgess-Bishop, J., Murray L, Rao, R., Marcus, E. A community effort to reduce the black/white breast cancer mortality disparity in Chicago. *Cancer Causes Control*, Published online 18 August, 2009

^{iv} Thompson et al, 1997

^v Rojas, 1996

^{vi} Lurie et al, 1997

^{vii} Antonucci et al, 1989

^{viii} Thompson et al, 1997