

# A Prospective Surveillance Model for Rehabilitation for Women With Breast Cancer

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**BACKGROUND:** The current model of care for individuals with breast cancer focuses on treatment of the disease, followed by ongoing surveillance to detect recurrence. This approach lacks attention to patients' physical and functional well-being. Breast cancer treatment sequelae can lead to physical impairments and functional limitations. Common impairments include pain, fatigue, upper-extremity dysfunction, lymphedema, weakness, joint arthralgia, neuropathy, weight gain, cardiovascular effects, and osteoporosis. Evidence supports prospective surveillance for early identification and treatment as a means to prevent or mitigate many of these concerns. This article proposes a prospective surveillance model for physical rehabilitation and exercise that can be integrated with disease treatment to create a more comprehensive approach to survivorship health care. The goals of the model are to promote surveillance for common physical impairments and functional limitations associated with breast cancer treatment; to provide education to facilitate early identification of impairments; to introduce rehabilitation and exercise intervention when physical impairments are identified; and to promote and support physical activity and exercise behaviors through the trajectory of disease treatment and survivorship. **METHODS:** The model is the result of a multidisciplinary meeting of research and clinical experts in breast cancer survivorship and representatives of relevant professional and advocacy organizations. **RESULTS/CONCLUSIONS:** The proposed model identifies time points during breast cancer care for assessment of and education about physical impairments. Ultimately, implementation of the model may influence incidence and severity of breast cancer treatment-related physical impairments. As such, the model seeks to optimize function during and after treatment and positively influence a growing survivorship community. *Cancer* 2012;118:(8 Suppl)2191-200. © 2012 American Cancer Society.

**KEYWORDS:** breast cancer, surveillance model, rehabilitation, survivorship care.

## INTRODUCTION

Treatments for breast cancer typically include surgery, chemotherapy, radiation therapy, and endocrine therapies, which introduce a variety of physiologic effects known to adversely impact body structure and function.<sup>1-8</sup> Treatment effects may lead to physical impairments including pain, fatigue, lymphedema, weakness, restricted range of motion, joint arthralgia, neuropathy, and osteoporosis.<sup>9-27</sup> Treatment also is known to adversely affect physical function, body weight, and cardiovascular health.<sup>28-33</sup> These impairments may adversely affect patients' participation in activities of daily living and employment and negatively affect healthy lifestyle behaviors such as regular exercise.<sup>34-41</sup> Although there may be a clinical impression that these issues are uncommon, emerging evidence indicates that a majority of women experience 1 or more of these physical impairments and suffer from the aggregate burden of impairments, comorbidities, and disease treatment.<sup>42-44</sup> When breast cancer-related physical impairments occur, they often go unrecognized and untreated, eventually reaching levels that negatively impact function.<sup>45,46</sup> Because breast cancer is the most common cancer diagnosed in women with relatively high overall survival rates, a comprehensive model of survivorship care that focuses on improving the physical function of women living with breast cancer is needed.

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The articles in this supplement were commissioned based on presentations and deliberations at a *Roundtable Meeting on a Prospective Model of Care for Breast Cancer Rehabilitation*, held February 24-25, 2011, at the American Cancer Society National Home Office, in Atlanta, Georgia.

The opinions or views expressed in this supplement are those of the authors, and do not necessarily reflect the opinions or recommendations of the editors or the American Cancer Society.

The views expressed in this article are those of the author(s) and do not necessarily reflect the official policies of the Department of Navy, Department of Defense, nor the US Government.

**DOI:** 10.1002/cncr.27476, **Received:** June 22, 2011; **Accepted:** August 10, 2011, **Published online** April 6, 2012 in Wiley Online Library (wileyonlinelibrary.com)

A seminal 2005 report by the Institute of Medicine highlighted the lack of comprehensive care for cancer survivors and issued recommendations to target improved survivorship care.<sup>47</sup> To this end, new initiatives have emerged in survivorship-care planning to define and address needs in follow-up care after breast cancer treatments.<sup>48</sup> These efforts focus on monitoring for disease recurrence and late effects of treatment. However, physical and functional recovery after breast cancer treatment has been relatively neglected. Considering the growing body of literature supporting oncology rehabilitation and its potential to mitigate or prevent physical impairment and functional decline in cancer patients,<sup>9,49-60</sup> there is an urgent need to consider ways to meet the rehabilitative needs for women treated for breast cancer.

The purposes of this article are to introduce a prospective surveillance model (PSM) of care for breast cancer physical rehabilitation derived from discussions at a 1.5-day meeting supported by the American Cancer Society, to describe the details and goals of the model, and to present a meeting discussion summary. The evidence base supporting the need for this model and a deeper discussion of cost and implementation issues are provided in accompanying articles in this supplement.<sup>44,61-72</sup>

### **Methods and Meeting Deliberations**

The meeting assembled a multidisciplinary core panel of researchers and expert clinicians who deliberated and discussed evidence for a PSM of care, targeting identification and treatment of early physical impairments and functional limitations in breast cancer survivors. The meeting included presentations, open deliberations by the core panel, and ample discussion time with stakeholder participants. The core panel represented a broad array of breast cancer researchers and clinicians with experience in issues pertaining to breast cancer survivorship, exercise, and rehabilitation. The introductory article to this supplement provides a list of core panel participants. In addition, stakeholders from major professional organizations; breast cancer patient advocacy, lymphedema, and educational organizations; and government agencies participated in the meeting. The purpose of stakeholder involvement was to: 1) enhance development of the model based on a broad array of experience with patient needs and the current context of care delivery; 2) prepare their organizations for potential roles in dissemination and implementation of a PSM.

Physical impairments to be addressed were identified before the meeting based on relative prevalence and potential for impact on function, and included pain, fa-

tigue, upper-extremity dysfunction, lymphedema, weakness, joint arthralgia, neuropathy, adverse effects on the cardiovascular system, and osteoporosis. The issue of weight gain/weight management was added to the impairment list based on feedback from meeting participants. The meeting was structured around 4 key evidence-based presentations: 1) descriptive epidemiology of physical impairments and functional limitations specific to breast cancer and its treatment; 2) clinical identification and diagnosis of common physical impairments; 3) efficacy of prevention and treatment interventions; 4) key elements for a prospective surveillance model of care.

Participants generally agreed that there is evidence to support the prevalence of physical impairments and functional limitations among breast cancer survivors and a potential for early rehabilitation intervention to prevent or mitigate many of these treatment effects.<sup>40,50,55,73-76</sup> At the conclusion of the meeting, a draft of the PSM was presented and discussed in a general session with all meeting participants.

### **Prospective Model of Surveillance**

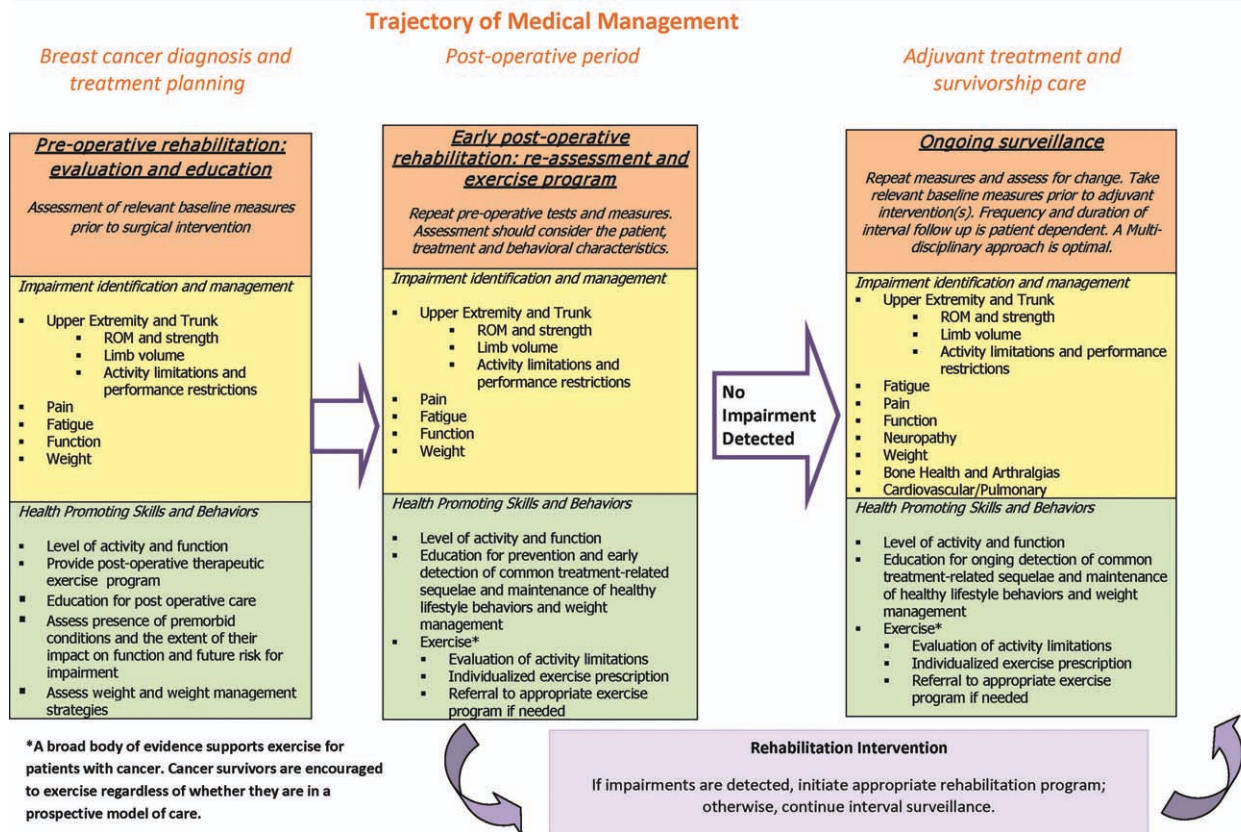
In oncology rehabilitation, prospective surveillance has been defined as a proactive approach to periodically examining patients and providing ongoing assessment during and after disease treatment, often in the absence of impairment, in an effort to enable early detection of and intervention for physical impairments known to be associated with cancer treatment.<sup>77</sup>

The goals of the PSM are:

- To promote surveillance for common physical impairments and functional limitations associated with breast cancer treatment.
- To provide education to reduce risk or prevent adverse events and facilitate early identification of physical impairments and functional limitations.
- To introduce rehabilitation and exercise interventions when physical impairments are identified.
- To promote and support physical activity, exercise, and weight-management behaviors through the trajectory of disease treatment and survivorship.

A PSM of care providing evidence-based clinical assessment using valid tests and measures has clinical utility.<sup>14,49,75,78-80</sup> The model seeks to ensure that physical impairments, function, and exercise are assessed and managed proactively and periodically throughout the course of breast cancer treatment and survivorship to expedite implementation of exercise and rehabilitation strategies

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**Figure 1.** A prospective surveillance model for physical rehabilitation for women with breast cancer.

known to alleviate these impairments.<sup>81,82</sup> Specific rehabilitation interventions are not addressed by the model.

Figure 1 depicts the PSM of care. The PSM is not a stand-alone plan for survivorship care but is designed to be incorporated into existing and emerging multidisciplinary survivorship care. Comprehensive rehabilitation assessment is not accomplished in a single visit, and ideally patients will be seen for multiple visits during and after cancer treatment.

The two primary components within the PSM, generally extrapolated from the Chronic Care Model,<sup>83</sup> are: 1) impairment identification and management, including comanagement of treatment effects with other members of the oncology care team; 2) health-promoting skills and behaviors. A summary of the key features of these components are outlined below.

### Impairment identification and management

This component highlights common physical impairments that may be seen at various intervals of dis-

ease management. Assessment uses tests and measures known to identify physical impairments and coincides with standard follow-up appointments for disease management and recurrence surveillance. This comanagement approach serves as a mechanism to integrate medical management of treatment effects with an individualized exercise and rehabilitation prescription and enables referral to other providers for further evaluation or treatment as appropriate.

### Facilitation of health-promoting skills and behaviors

This component highlights assessment of the patient's level of exercise, physical activity habits, and functional status in a relatively normal state of health. The model provides advice and education for initiating exercise, promoting weight management, and introducing ongoing, community-based exercise that the patient can perform independently or with provider monitoring. Education prepares patients to recognize and act on

symptoms consistent with adverse effects over the course of recovery, enabling self-monitoring and self-management through patient activation.

Rehabilitation assessment phases in the PSM are preoperative, early postoperative, and ongoing surveillance. Entry into the PSM model occurs around the preoperative and postoperative period because surgery is the first intervention for the majority of breast cancer patients. The PSM, therefore, will be most relevant for newly diagnosed women with stage 0-III breast cancer before and after breast-conserving surgery or mastectomy, with or without reconstruction. Women with stage IV breast cancer have significant aggregate effects of treatment that may also benefit from rehabilitation intervention.<sup>84</sup> Although the PSM does not address these women specifically, it is anticipated that the ongoing surveillance phase of the model will enhance access to rehabilitation care and exercise for women with metastatic breast cancer.

#### **Preoperative rehabilitation: evaluation and education**

Premorbid level of function, current exercise habits, prior physical impairments, and other comorbidities are assessed to establish a baseline from which to follow the patient and detect change over time. Specifically, upper-extremity range of motion, volume, and strength, as well as body weight, function, fatigue, and level of physical activity and exercise should be assessed at the preoperative visit. In addition, this visit allows for education regarding the postoperative plan of care, including postoperative rehabilitative exercises, advice for weight control, and advice for returning to activities during and after treatment, as well as discussion regarding known risk factors for adverse effects of the treatment plan.

Arguments have been made that informing patients about potential adverse effects of treatment can engender unnecessary fears. Although health care providers should be sensitive to patients' reactions to information about treatment adverse effects, patients consistently express the need for information before treatment and especially before developing physical impairments,<sup>62,85-88</sup> as reflected in the patient perspective article in this supplement.

#### **Early postoperative rehabilitation: reassessment and exercise program**

Evidence suggests that upper-extremity range-of-motion exercise should be initiated 1-2 weeks after surgery, and an early postoperative reassessment visit should take place within the first month after surgery.<sup>89-92</sup> This visit repeats baseline tests and measures and further rein-

forces education regarding weight control, exercise, and return to activity. Some level of surgical sequelae will be present at this visit and, if functional limitations are noted, rehabilitation intervention may be initiated.

This reassessment visit also provides an opportunity for patient education on prevention and early detection of common treatment-related impairments as well as education about exercise and health-promoting behaviors. An individualized exercise program is prescribed for independent exercise throughout the course of cancer treatment, aimed at improving function and preventing impairments related to treatment.<sup>93</sup> It should be emphasized that evaluation by a rehabilitation specialist is not needed for women to begin following the American College of Sports Medicine (ACSM) and UK recommendations of aerobic activity for at least 150 minutes weekly during and after cancer treatment.<sup>94,95</sup>

#### **Ongoing surveillance**

Baseline tests and measures are repeated at each follow-up visit in an effort to identify changes and to detect early signs of physical impairment. If impairments are detected, rehabilitation may be initiated. This proactive approach promotes early intervention to optimize recovery and return to premorbid levels of function.<sup>54,75,89</sup>

Additional assessments should take place at these visits specific to the treatments outlined in the cancer plan of care. For example, patients who will receive a neurotoxic chemotherapy agent should have sensory and balance screening before initiation of the chemotherapy to enable ongoing monitoring for physical impairments. Assessment findings may warrant referral back to the medical oncology team or to other care providers.

Ongoing education is vital to heighten the patient's awareness of potential late effects from treatment and to promote a proactive approach to their diagnosis and treatment. In addition, reinforcement of health-promoting behaviors such as exercise, weight control, and physical activity continues.<sup>96</sup> Finally, the model supports education for exercise promotion regardless of presence or absence of impairments.<sup>97-99</sup>

#### ***Panel Perspectives and Discussion Points on the Prospective Surveillance Model***

The panel of experts endorsed the concept of a PSM for early identification of breast cancer-related impairments. Overall, the panel noted that significant disparities exist in referral patterns for physical rehabilitation and that a concerted, streamlined method is needed to remedy this. Major areas of discussion on elements of the model included: facilitation of early identification of



impairments and reduced time to rehabilitation intervention; inclusion of all breast cancer patients versus those at high risk for impairment; patient burden; facilitation of exercise; provision of evidence-based patient education; provider barriers and potential cost impact.

Differing viewpoints were raised about several issues related to the model, including the ability of health care settings to implement such a model; the demands placed on providers both in knowledge and in capacity to implement the model; who should be responsible for ongoing assessment and coordination of the model; the potential for the model to be a barrier to independent exercise; whether there is truly a need for a model like this in addition to the rehabilitation care already being rendered to patients; and whether this model is applicable to every patient undergoing treatment.

#### **Early identification of impairments and reduced time to rehabilitation intervention**

The panel supported the premise that prospective surveillance offers the potential to put a patient and her care team ahead of pending functional limitations by making rehabilitation an integral part of breast cancer care. The importance of such a model is that early intervention is enabled more rapidly than in a traditional, impairment-based model.

#### **Inclusion of all breast cancer patients versus risk-based triage approach to rehabilitation referral**

A recurring question raised by the panel was the extent to which every breast cancer patient needs to be included in the model. Disparate viewpoints were raised about the need for all patients to receive care through prospective surveillance. Some patients may experience little or no adverse effects during or after treatment, prompting the question: Is this model of surveillance necessary for every patient? Counterpoints were made as to the compelling data that at each point along the continuum of care and with each intervention offered, there are potential physical impairments that might be prevented or mitigated using the PSM.

When panel members were asked to identify the group of patients for whom the model does not apply, discussion centered on the issue of risk for impairments. The point was made that being low risk during treatment does not necessarily translate into being low risk in the future, considering what is known about late effects of treatment.

There was further discussion about a possible triage approach that would include a screening tool for symptom identification and risk assessment to trigger referral to reha-

bilitation for early treatment of physical impairments. A counterpoint to this suggestion was made by rehabilitation professionals on the panel that this is the current approach used and has proven to be ineffective in promoting early detection and intervention. Although the symptom-based triage approach would prompt questions about physical impairment and function, it relies on functionally disabling problems to be reported by the patient. Evidence exists that even among metastatic breast cancer survivors in a health care system with outstanding rehabilitation services on site, few patients are referred for help with physical impairments or function, even among those with difficulty ambulating.<sup>45</sup> In addition, the current structure of waiting for patients to self-identify a need for rehabilitation is insufficient to enable early identification. The PSM could incorporate a triage system that would utilize an impairment- and risk-screening tool in every patient, with a validated set of questions in which certain responses would trigger automatic referral to rehabilitation needs to be evaluated.

#### **Patient burden**

Panel discussions supported the premise that prospective surveillance may aid in reducing patient burden through ongoing assessment by professionals with expertise in function and exercise. A rehabilitation or exercise professional who is knowledgeable in oncology rehabilitation can be a resource to advise the patient about known adverse effects of disease treatment, thus providing an opportunity to mitigate patient burden. Dissenting viewpoints included concern that adding visits to yet another health care provider during the course of treatment presents an additional burden for patients. Proximity of the rehabilitation provider to others on the patient's health care team was of concern; patients may be required to travel farther to see the provider and, depending on their payer, may require additional paperwork and incur extra costs. Counterpoints were made that the model is structured to align with ongoing medical appointments and, if assessments are introduced from diagnosis as an integrated part of patient care, acceptance among patients may be improved. The literature supports the premise that women's needs for education and intervention for the adverse effects of breast cancer treatment appear to outweigh these perceived barriers to rehabilitation.<sup>40,100</sup>

In an article on patient perspectives in this supplement, Binkley et al. report that patients are often surprised and conflicted when faced with impairments and functional limitations during and after cancer treatment. They often hesitate to address these issues with their medical care team so as not to appear to complain about relatively

minor issues. Fear is also a significant burden experienced by the patient.<sup>101</sup> Will she do harm by exercising? Should she push herself through fatigue or through pain or will it make things worse? The panel agreed that, in general, the education points offered by the PSM could help to alleviate this burden for the patient.

### Facilitation of exercise

Panel members agreed that the model should expressly encourage patients, at all phases of disease treatment, to engage in exercise. Efforts to implement this model should emphasize means to facilitate exercise and avoid perceptions of increasing barriers to exercise. Concerns were raised that a model such as this could become a barrier to facilitating exercise programs that are community based or of the individual's own volition. Whether the proposed system would increase or decrease exercise among survivors is a testable hypothesis.

Various stakeholders highlighted unique, community-based exercise programs through groups such as the YMCA (in conjunction with Livestrong), which provide oncology-specific exercise guidance and are popular throughout the US, as well as *Reach to Recovery*, which provides individualized recovery instruction, and other programs.<sup>102</sup> The panel emphasized the important role that community organizations and patient advocacy groups could play in promoting exercise, weight management, and healthy lifestyle behaviors so that patients access such programs in a timely manner, before experiencing functional decline.

### Provision of evidence-based education and advice

Currently, information about physical function and exercise is provided in a fragmented manner; some panel members and patients noted that information could be conflicting among various providers on the health care team. Panelists recognized that the PSM, integrated within multidisciplinary breast cancer care, could contribute to consistent guidance and promote return to full function and activity levels. Patients noted the need to have streamlined care from diagnosis through treatment and beyond, by a provider who focuses on mobility, function, and physical activity.<sup>62</sup> The potential to integrate the PSM within burgeoning systems for providing survivorship health care is discussed in an accompanying article by Gerber et al.<sup>61</sup>

### Provider barriers

Although the panel recognized that there is increasing awareness of the sequelae associated with cancer treatments, many of which affect function, many oncology

and primary care providers may lack knowledge of and experience with reliable and valid screening tools and effective rehabilitative interventions to alleviate these sequelae. Health care providers who lack substantial exercise and rehabilitation expertise are often uncertain in making exercise prescriptions beyond broad, general recommendations. This creates a conundrum for patients who want to participate in daily life, activities, and exercise, knowing it is beneficial for them but not knowing how much they can participate without doing harm or causing further pain. Patients trust their providers and tend to follow their advice regarding initiation of exercise.<sup>103</sup>

The panel identified the model's potential to reduce burden on oncologic practitioners by providing a defined course of action for reducing impairments and restoring function. There was much discussion about who should provide baseline examinations and ongoing assessments to patients. The rehabilitation community is composed of physiatrists, physical therapists, occupational therapists, and exercise professionals who are experts in function and are likely knowledgeable in this area. Core panel members as well as stakeholders representing various rehabilitation professional associations noted that there are not nearly enough professionals practicing in oncology specialty areas to accommodate the needs of all breast cancer patients. The panel agreed that although rehabilitation and exercise professionals are the preferred providers in these domains, there is an ongoing need to educate physicians, nurses, physician assistants, nurse practitioners, and other health care providers about prospective surveillance for early detection of impairments and prompt referral for patients to receive intervention.

### Cost impact

The panel agreed that there are minimal data on the cost burden of treating physical impairments related to cancer treatment and that it would be premature to make any claim that such a program would positively impact the cost of health care or unreasonably increase costs. This issue is discussed in greater detail by Cheville et al. in an accompanying article in this supplement.<sup>72</sup>

### Rationale for Prospective Surveillance

Cancer treatments carry with them a number of adverse physiologic effects that can escalate during active disease treatment (ie, surgery, chemotherapy, radiation, and endocrine therapy) but may resolve spontaneously upon treatment withdrawal.<sup>104-106</sup> Whereas some adverse effects contribute to early physical impairments, others occur months or years after treatment is withdrawn.<sup>3,8,12,107-110</sup> As a result of these impairments,

breast cancer patients often attenuate their activities and develop decreased tolerance to activity.<sup>38,40,85,111</sup> Patients have described the need for education about treatment-related impairments as well as information to help them return to exercise and activity.<sup>40,85</sup>

Although cancer treatment can lead to significant morbidity, many impairments respond to rehabilitation interventions.<sup>9,33,58</sup> Screening for physical impairments through a surveillance program that spans the treatment trajectory may help to expedite their identification and treatment. Studies demonstrate that rehabilitation care reduces the incidence of breast cancer–related physical impairments.<sup>75,79,112,113</sup> Prospective surveillance goes a step further by enabling early detection and treatment of these impairments, which may reduce short- and long-term morbidity.<sup>14,49,50,75,78,80,89,108,112</sup> Further, there is evidence to demonstrate improved impairment treatment outcomes—specifically regarding lymphedema, fatigue, and shoulder morbidity—with early intervention through a PSM.<sup>78,79,113,114</sup> These examples support a growing consensus that there is merit to including assessment for physical impairments in breast cancer follow-up.<sup>115</sup>

### Conclusions

Evidence supports the need for ongoing monitoring to detect and treat functional decline and to promote healthy lifestyles throughout treatment and survivorship, thus supporting the contention that ongoing surveillance should be part of the patient's plan of care from diagnosis.<sup>11,116-118</sup> The current system for breast cancer care provides a structured avenue to disseminate the proposed approach to prospective surveillance. This would require an organized plan for implementation and would rely on a collaborative effort among stakeholders including health care providers, patients, health care professional organizations, government agencies, and patient advocacy groups. The final article in this supplement provides a synopsis of stakeholder perspectives on the model and feasibility of its implementation.<sup>119</sup>

Never before have breast cancer patients had a dedicated plan to guide functional rehabilitation, identify exercise prescription, and promote health behaviors during and after cancer treatment. The PSM for early detection of physical impairment provides such a framework and focuses on values that have been articulated by the survivors, namely return to needed and desired life activities. Because up to 80% of patients will attain full life expectancy, they should do so with full functional capabilities and without disability from cancer treatments that

can be readily identified and remedied within this prospective surveillance model of care.

### FUNDING SUPPORT

Support for this meeting and supplement was provided by the American Cancer Society, through The Longaberger Company®, a direct selling company offering home products including handcrafted baskets made in Ohio, and the Longaberger Horizon of Hope® Campaign, which provided a grant to the American Cancer Society for breast cancer research and education.

### CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

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