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Patient-Reported Outcomes Screening for Improved Patient Wellness: A Cancer Center Initiative

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Section I: Abstract

Background: People experiencing serious illness have significant unmet physical, emotional, social and spiritual needs. The Quality Oncology Practice Initiative (QOPI) requires patients to be screened for emotional wellbeing and pain by their second oncology visit. This project details one cancer center's quality improvement initiative to (a) implement electronic screening of every cancer patient by their second oncology visit, (b) design processes for ongoing assessment and intervention of need(s), and (c) develop measureable and sustainable evaluation metrics to ensure that palliative care needs are met. **Methods:** In June 2015, we launched electronic collection of patient-reported outcomes (PROs) using the Patient Reported Outcome Measurement Instrument System (PROMIS) global screen. Screening was completed via the health portal or clinic computer prior to the first return visit and at 30-day intervals. **Results:** The primary measures of interest were the percentage of completed PROMIS questionnaires and the percentage of *relevant answers,* with a target completion rate of 60%. The highest completion rate was 25.3%. Six weeks of *relevant answers* were collated from August 18, 2015 through September 30, 2015 with a range of 3.6% to 5.3% of patients having *relevant answers*. **Conclusions:** The utilization of a screening tool is only the method by which assessment and evaluation of comprehensive care needs is initiated. Evidence-based practice guidelines and clinical care pathways must also be in place to manage each symptom identified in a standardized way. Support for oncology nurses to lead assessment and connect patients with resources is an opportunity to incorporate primary palliative care into oncology practice.

Keywords: screening, screening tool, emotional wellbeing, patient-reported outcomes

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healthcare providers, address and manage the wellbeing of cancer patients. I have learned so much along this journey and have grown immensely, both personally and professionally. I had no idea when I chose to pursue my doctorate that it would be this enjoyable!

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Section II: Introduction

Approximately 14.5 million people in the United States are living with cancer today. It is estimated that by January 2024 this number will grow to include 19 million cancer survivors (American Cancer Society [ACS], 2014). This can be attributed to phenomenal breakthroughs in cancer research and progressive treatment modalities that lead to longer life expectancies for patients with cancer. Currently, nearly half of those surviving with cancer are 70 years or older (ACS, 2014). However, a chasm exists between these extraordinary innovations in treatment and the longitudinal impact these therapies have on the quality of life (QOL) of patients, including their relationships with family and friends.

Research indicates that patients with serious illness do not receive adequate symptom management and have unmet psychosocial needs leading to poor patient and family satisfaction (Meier, 2011; Wright et al., 2008). There is also literature demonstrating how comprehensive symptom and emotional well-being correlate with reduced symptom burden, which leads to enhanced quality of life (Kamal et al., 2013; Von Roenn & Temel, 2011). Furthermore, studies have revealed that clinicians do not adequately screen for emotional distress, physical, or psychological needs leaving a major gap in health care for these patients and contributing to poorer patient outcomes (Brooks et al., 2014; Meier, 2011; Ristevski, Breen, & Regan, 2011). Thus the question arises, how do oncology healthcare providers more effectively identify cancer patients in need of palliative care or other supportive services at the right time in their disease trajectory?

The Institute of Medicine (IOM, 2001) report *Improving Palliative Care for Cancer* brought awareness to the role of palliative care as a mechanism toward better management of complex symptoms and psychosocial issues, and called for improved access to palliative care

services. Over 10 years later, the American Society of Clinical Oncology (ASCO) published a provisional clinical opinion (PCO) stating that the combination of standard oncology care with palliative care leads to better patient and caregiver outcomes. This PCO is supported by seven published randomized controlled trials (RCTs) validating the feasibility of providing palliative care concurrent with routine oncology care (Smith et al., 2012). The most significant of these studies is a phase III RCT conducted by Temel et al. (2010) with patients who have metastatic non-small-cell lung cancer (NSCLC). The findings of this study revealed an increased QOL (98.0 vs. 91.5 [high scores indicating better QOL], $p = 0.03$) and a decrease of depressive symptoms (16% vs. 38%, $p = 0.01$) among the study group. A surprising finding was the median survival rate: patients survived longer in the intervention group (11.6 months vs. 8.9 months, $p = 0.02$) despite a decrease in the aggressiveness of end-of-life care (33% vs. 54%, $p = 0.05$).

The second noteworthy RCT was the first study to evaluate the concurrent use of palliative care with oncology care through a nurse-led intervention. Bakitas et al. (2009) measured QOL, symptom intensity, mood, and resource use among 322 patients with several types of advanced cancer using a variety of assessment tools. At baseline, there were no statistically significant differences between the two groups. Nevertheless, longitudinal intention-to-treat analyses for the total sample revealed higher QOL ($p = 0.02$) and depressed mood ($p = 0.02$), but no truly significant decrease in symptom intensity ($p = 0.06$) for the intervention group compared to the control group. Despite negative results, Bakitas et al. (2009) were pioneers in initiating the exploration of various palliative care interventions (for example, the relationship of education, open communication, family support, and resource navigation and management on patient and family overall wellbeing) and positive outcomes.

Palliative care is estimated to save the United States health care system $1.2 billion per year over current inpatient utilization levels. This savings projection could increase to $4 billion annually if palliative care capacity expanded to meet the needs of six percent of hospital discharges at 90% of hospitals (with a minimum of 50 beds) in the United States. Hospice care is projected to save an average of $2,300 per hospice beneficiary, yielding an overall savings of more than $3.5 billion a year (Meier, 2011).

To date, there are no studies that have reviewed the cost impact of palliative care on an outpatient oncology care program. One reasonable explanation may be the complexity of determining how to capture and assess the true costs of palliative care. There are direct and indirect costs that are often overlooked, but should be considered when evaluating the cost effectiveness of palliative medicine. The direct costs include the expenses of medications, procedures and diagnostic tests, and the salaries of healthcare providers (e.g., RNs, physicians, social workers, and advanced practice providers). Direct non-healthcare costs include expenses outside of the walls of Stanford Cancer Institute (SCI). These expenses include in-home healthcare services, transportation to and from appointments, child-care costs, or assistive equipment. Indirect costs (e.g. the inability to attend work or school, or carry out activities of daily living) impact the illness and access to treatment for patients and their caregiver(s) (Simeons et al., 2010).

Though it is difficult to place a monetary value on improved QOL, studies show that early referral to hospice and less money spent on futile medical interventions in the last months of life has resulted in cost savings (Meier, 2011; Wright et al., 2008). Furthermore, a recent study by Seow et al. (2014) retrospectively reviewed the impact of community-based palliative care in the province of Canada. Their retrospective cohort study found that patients receiving palliative

care, across all the palliative care teams in the province, had an overall lower number of hospitalizations and emergency department visits in the last two weeks of life, and were less likely to die in the hospital compared to their matched control group receiving usual care (Seow et al., 2014).

As palliative medicine has continued to evolve, so has the complexity of the care required by cancer patients (Higginson & Evans, 2010). In a systematic review of 44 studies (involving 25,074 patients), Teunissen et al. (2007) identified 37 symptoms common to more than 10% of patients. Fatigue, pain, lack of energy, weakness, and loss of appetite were the most common symptoms reported. Interestingly, the most significant finding, and consequent limitation of this study, was the inconsistency among symptom assessment methods, which led to varying degrees of symptom prevalence responses. As a recommendation, Teunissen et al. encourage the utilization of a standardized comprehensive assessment tool, such as a questionnaire, to further capture the true essence of symptom burden among these patients. This recommendation along with ASCO and the National Cancer Care Network (NCCN), collectively advocate for the integration of palliative care into cancer care (NCCN, 2014; Smith et al., 2012). Furthermore, the Center to Advance Palliative Care (CAPC), a nationally-recognized organization committed to palliative care growth and development, recommends the use of a screening tool(s) for assessment of physical, emotional/psychosocial, medical, or spiritual needs (CAPC, 2011). The two RCTs by Temel et al. (2010) and Bakitas et al. (2009) operationalize these recommendations and demonstrate how screening tools can effectively measure and evaluate patient-specific palliative care needs.

From these recommendations came the impetus for this evidence-based practice change project: to implement screening for comprehensive care needs of cancer patients from early

diagnosis and throughout their disease trajectory to increase patient access to supportive care services, improve symptom management, and enhance QOL. This project encompassed the implementation of a screening tool and the development of standard processes to ensure patients had the opportunity to complete the questionnaire so that identified needs could be identified, addressed, managed, and monitored by the appropriate clinical care team member(s). This project is still undergoing iterative changes and development however, preliminary analysis reveals promising results.

Background Knowledge

Description of setting. This evidence-based, change-of-practice project took place at the Stanford Cancer Institute (SCI), which is a part of Stanford Health Care (SHC) (see Appendix A for institution's permission). SHC is a prominent Bay Area and world-renowned institution, and holds a reputation for excellence in patient care. The institution is highly respected for expertise in cardiac care, cancer treatment, neurosciences, surgery, and organ transplants. Patients travel from neighboring cities, distant states, and around the world to receive exceptional general acute care services and tertiary medical care. This academic teaching institution employs 1,907 hospital medical staff – a combination of full-time faculty and physicians – and houses 1,044 interns and residents. In addition, they have a nursing workforce of over 2,300 registered nurses (RNs). SHC partners with Stanford University School of Medicine, the oldest school in the Western United States, to foster excellence in the translation of knowledge into quality and efficacious patient care (Stanford University, 2014).

Stanford Clinics, a medical group comprised of 493 full-time faculty physicians at the Stanford School of Medicine, is a division of SHC. Over 100 specialty care services are offered by Stanford Clinics to a diverse population of patients. The SCI houses several of these specialty

clinics, providing treatment for 22 different cancer diagnoses. SCI houses a radiation therapy site, a mammography and diagnostic radiology unit, multimodality cancer clinics, an infusion treatment area, a learning center, social services, nutritional services, a tumor registry, a pharmacy, an academic and clinical research site, and a conference center. Treatment is provided by both physicians and scientists, along with a robust interdisciplinary healthcare team, who partner together to treat all forms of cancer. The mission of SHC is "to care, to educate, to discover," and this mission is integrated into daily clinical and operational activities (Stanford School of Medicine, 2014a).

SCI has achieved the distinguished designation as a National Cancer Institute and is a founding member of the National Comprehensive Cancer Network (NCCN), an alliance of 23 of the world's leading cancer centers devoted to improving the quality and effectiveness of the care cancer patients receive. The SCI sees approximately 200 new patients per month. In addition, they have an average of 1,100 returning SCI visits per month, and a total of 15,700 SCI patient visits per year. SHC is consistently recognized by U.S. News and World Report as a top hospital in the nation for cancer care. Other prestigious awards include Magnet status and a certified Quality Oncology Practice Institute by ASCO (Stanford School of Medicine, 2014a; Stanford School of Medicine 2014b).

Palliative medicine at SHC. Palliative medicine (PM) is a specialty service comprised of an interdisciplinary group of clinicians who are devoted to mitigating symptoms that plague patients with chronic disease and have the expert training in managing the long-term psychological, social, emotional, physical, and spiritual effects of the disease and its treatment(s) (Glare et al., 2013; Ristevski, Breen, & Regan, 2011). SHC has had an inpatient PM program since 2007. This team is comprised of four physicians, four advanced practice nurses, one social

worker, and one fellow (who rotates through this service every two to four weeks). This team is a consult service; they receive consult requests from an inpatient referring care team and maintain contact with the patient and primary team throughout the patient's hospitalization. They make recommendations to the primary care team based on their assessment and expertise. If appropriate, the inpatient PM team will refer the patient to outpatient PM upon discharge.

In 2012 the program's leadership, recognizing patients' palliative care needs extend beyond the acute care setting, expanded to the outpatient setting. The outpatient PM team consists of three physicians, two advanced practice nurses, three social workers, one chaplain, and one clinic administrative assistant. This team operates five days a week and also sees patients based on referrals from a variety of patient care teams. Their goal is to see patients within one week of referral and on an ongoing basis based on patient need, unless they receive an *urgent* same-day referral. Currently, they have over 100 patient encounters per month. Although the infrastructure is in place, a gap analysis identified several opportunities to improve how palliative medicine was implemented throughout the organization and advance the delivery of palliative care.

Gap analysis and identification of care problem. Primary efforts to discover how to better identify patients in need of palliative care services and how to better provide them these services began with chart review. Retrospective chart reviews were performed on all patients from one gynecologic oncology clinic at SCI (n = 120) between June 2014 and February 2015 to assess whether they were screened via the Patient Reported Outcomes Instrument Measurement System (PROMIS) for palliative medicine needs at their new patient visit. More specifically, chart reviews were conducted to identify the percentage of new patients screened, the percentage of patients who screened positive based on NCCN criteria, and the percentage of patients

referred to PM (see Appendix B for NCCN Palliative Care Screening Guidelines; see Appendix C for results from chart review). Fifty percent of the cohort of patients were screened using the instrument. Less than five percent were referred to PM. However, the chart review revealed that 40% of all patients met NCCN criteria for referral to PM. Referrals to other support services based on screening included oncology social work and survivorship.

One salient finding from this gap analysis, supported by the literature, recognized that patients were referred to palliative care late in their disease trajectory or not at all (Hui & Bruera, 2015; Meier, 2011; Temel et al., 2010). Interviews conducted with patients, families, and oncologists at SCI further revealed that cancer patients were not routinely or comprehensively screened for palliative medicine needs. Consequently, it was determined a standard process needed to be employed to capture a broader array of cancer patients to identify palliative care needs earlier in their cancer journey (see Appendix D for a gap analysis inspired by the Chronic Care Model; Appendix E for an overview of current state of palliative care at SHC/SCI).

An additional finding from the gap analysis indicated misconceptions and biases from clinicians and patients alike that palliative care impeded screening, referral, and access to services. Screening for comprehensive care needs with ongoing assessment and management of needs is an important component to providing quality patient and family-centered cancer care (Hui & Bruera, 2015; Kamal et al., 2014). Yet despite its existence for close to a decade, there continues to be variance in how palliative care is understood and employed both at an institutional level as well as across the nation and internationally (Glare, 2013; Greer, Jackson, Meier, & Temel, 2013). Efforts to establish a non-threatening, clear, concise, and compelling brand for PM at SHC are ongoing in order to dissuade misperceptions and promote greater access to supportive services for patients and family members. Seventy percent of healthcare

systems have a palliative medicine program; however, 70% of Americans report they are "not at all knowledgeable" about palliative care (Parikh, Kirch, Smith, & Temel, 2013, p. 2347).

Fortunately, SHC has embraced the specialty of PM and has assembled a robust interdisciplinary team of palliative medicine clinicians who provide specialty palliative care services as well as mentor primary patient care teams in practicing basic palliative care. Furthermore, it was the request of the SCI leadership team to implement a screening tool and design a process to identify and manage palliative care needs, allowing for timely project initiation and eliminating the potential barrier to stakeholder buy-in.

Local Problem

Current models of care at SHC do not routinely incorporate patient and family feedback into the design, operation, or outcome evaluation into cancer care programs. In addition, SHC currently has no standardized method of capturing palliative care needs of the cancer patients they serve. Screening, assessment, and management of needs is fragmented and the process of making referrals lacks consistency and clarity. Studies have shown that early integration of palliative medicine into cancer care improves outcomes including quality of life, care coordination, and survival (Glare et al., 2013; Hui & Bruera, 2015; Kamal et al., 2014). Expert groups (e.g., American Academy of Hospice and Palliative Medicine, American Society of Clinical Oncology, Center to Advance Palliative Care, and National Comprehensive Care Network) recommend early integration of palliative and oncologic care for the best possible outcomes.

Despite its growing reputation, there is much variability in how palliative care is understood, utilized, implemented, and measured throughout the U.S. healthcare system (Glare, 2013; Greer et al., 2013), and it is true also for SHC. Through the chart reviews from 120

patients with gynecological cancers and qualitative information gathered from patients, their families, and a variety of clinicians, it is apparent that lack of process and ownership of follow-up, assessment, and management of responses to the PROMIS screening left patient's needs largely unacknowledged by the system. While a standardized process for screening is necessary, resources for assessment and management are also required.

Intended Improvement

It is well documented in the literature that emotional and physical distress in cancer patients is underreported and undertreated (Wagner et al., 2015**)**. Early identification of palliative care needs and integration of palliative care services into routine oncology care is essential to adequately meet the complex care needs of patients and improve quality of life outcomes (Glare et al., 2013; Parikh et al., 2013; Meier, 2011; Temel et al., 2010). Evidence supports the use of a screening tool along with clinical care pathways to assist care teams in meeting the comprehensive care needs of patients in a systematic and standardized way (Chen, Ou, & Hollis, 2013; Carlson et al., 2012; Dudgeon et al., 2012; Bush et al., 2010; Bultz & Groff, 2009; Khatcheressian et al., 2005; NIH, 2004). Most recently, the Quality Oncology Practice Initiative (QOPI) requires patients to be screened for emotional wellbeing and pain by their second oncology visit. This is a standard of care required for accreditation (ASCO, n.d.).

This evidence-based project details the quality improvement initiative to (a) utilize patient reported outcomes (PRO) screening to identify patient distress and wellbeing, (b) develop adaptive nurse-led algorithms to assess and intervene for unmet needs, and (c) to provide standardized clinical care pathways for care and management. Evaluation will initially include measurement of the number and percentage of screening instruments completed, the number and percentage with identified needs (termed *relevant answers*), and the number and percentage of

patients referred to supportive services, mainly palliative care and social work, as a result of PROMIS screening. More development is needed for evaluating if patients feel their needs are met.

Project aim. By December 2015, every new patient with a cancer diagnosis coming to SCI will be electronically screened using PROMIS by their second oncology visit. The purpose of this project is to establish an evidence-based process for screening cancer patients for comprehensive care needs (e.g. physical, social, emotional, and spiritual wellbeing), as well as to design processes for ongoing assessment and intervention of need(s), and develop measureable and sustainable evaluation metrics to ensure that palliative care needs are met.

Goals. The primary goal of this project is to implement an electronic screening tool to identify patient's supportive care needs with the target of screening all new cancer patients for distress by their second visit to SCI and every 30 days thereafter. Project performance goals are to ensure all patients with supportive care needs or *relevant answers*, as indicated by a response of *fair* or *poor* on the PROMIS tool, are addressed and/or referred to the appropriate supportive care service(s) in a timely manner. End goals include improvement in symptoms and psychosocial health, and better resource utilization (e.g. decrease emergency department visits and inpatient hospital admissions) resulting in significant enhancements to patient wellbeing and health care cost savings. These goals are supported by the project's objectives, which are to increase access to supportive care services in the outpatient setting for patients with a cancer diagnosis; create an infrastructure for clinicians and patients to ensure routine completion of PROMIS; and develop a streamlined process for evaluation, follow-up, and monitoring of identified patient needs.

Trigger for change: Transformation. The foundation for this evidence-based practice change project was born out of the Stanford Cancer Initiative, which is a five-year project shared by Stanford School of Medicine and SHC to develop and implement a new model of cancer care. This new model combines cutting edge science and technology with an intentional focus on individual patient-specific needs. The four main areas of influence through *Transformation* include creating a new standard of cancer care, targeting the toughest cancers, capturing the power of cancer science, and seizing innovations. This project is funded by a $125 million donation by a group of generous donors with the intent to raise another $125 million by the Stanford School of Medicine (SCI, 2013).

From this initiative and under the *Transformation* category of "creating a new standard of cancer care" came the idea to redesign the patient and family experience for the purpose of building a new palliative care program that is truly centered on patient and families (SCI, 2013). The ultimate goal of this program is to provide evidence-based medical care that is in alignment with patient goals and values, and to minimize unwanted or unnecessary medical interventions. The objectives of this redesign project are the following:

- to determine the appropriate model of care delivery of PM desired by cancer patients and their family members/care providers;
- to determine the best operational means to deliver the optimal model of PM for patients and their families, again based on patient and caregiver needs;
- to develop and measure appropriate outcomes for the PM model of care, for providers, patients, and caregivers (E. Tribett, personal communication, September 11, 2015).

This is a three-year project and is currently in its second year. This specific redesign project received an additional $500,000 gift from one generous cancer patient and her husband to

be used only by Dr. Ramchandran for the purposes of creating a better cancer care experience through better utilization of palliative medicine. This author's evidence-based practice project is a component of this larger project to redesign the palliative medicine program at SHC.

Review of the Evidence

Early palliative care. In 2012, the American Society of Clinical Oncology (ASCO) published a provisional clinical opinion (PCO) stating, when combined with standard oncology care, palliative care leads to better patient and caregiver outcomes. ASCO openly recognizes this PCO is not supported by robust data; however, there have been seven published randomized controlled trials (RCTs) validating the feasibility of providing palliative care alongside routine oncology care (Smith et al., 2012). In addition to the studies by Temel et al. (2010) and Bakitas et al. (2009), Greer et al. (2013) published a comprehensive review advocating the integration of palliative care into oncology care early in the disease process, specifically for patients with advanced cancer.

Greer et al. (2013) acknowledged the dearth of evidence and limited funding available to support the delivery and dissemination of palliative care services. Nevertheless, they recognized the need for attention and the development of clinical guidelines to manage the burdensome side effects of cancer treatment. The review discussed concurrent models of palliative care delivery in the outpatient setting as well as provided evidence-based rationales for the early integration of palliative care into cancer care: high symptom burden for patients with advanced disease, varying prognostic awareness that results in uninformed treatment decision-making, poor utilization of resources, late access to end-of-life care, and unnecessarily high treatment costs.

While focus on staging and treatment protocols is important, Greer at al. (2013) emphasized the need to address the emotional and spiritual distress that accompanies such a

diagnosis. The recognition of these symptoms often includes some combination of anxiety, depression, and/or adjustment disorders, and can aid in establishing a strong patient/caregiver-provider relationship. In turn, this relationship leads to greater trust, and decreased psychosocial distress, with the hope of improving advanced care planning, end-of-life care planning, and discussing resuscitation preferences earlier on in the disease process.

Palliative care teams also help translate prognostic information into comprehensible disease awareness, which helps maintain costs. Greater understanding of disease prognosis improves communication, assists in realistic decision-making throughout the course of the patient's illness, and helps allay anxiety and fear. Greer et al. (2013) and Wright et al. (2008) dispel the myth that conversations about preferences for care (e.g. advance directives) do not increase depression and worry, rather they decrease feelings of depression, anxiety, and hopelessness. Greer et al. (2013) summarized the findings of several studies and all agreed on the need to decrease unnecessary costs (those that are beyond the point of evidence of benefit) through the implementation of quality metrics to help determine high-quality cancer care across the spectrum.

The authors also discussed the model of co-management between oncology and palliative care providers based on pilot feasibility studies and two RCTs. Conclusions support the use of the integrated or embedded model promoting the comanagement of care: the oncologist directs cancer-specific treatments and the palliative care team focuses on the physical symptoms and psychosocial concerns. While there are some limitations to this model (e.g. patients have to have a higher performance status for outpatient care visits) the potential to improve resource utilization through complementary comanagement of one's illness is promising. In this model, patient symptoms are addressed as they emerge, reducing the likelihood they will seek care in the

emergency department, as well as reducing the chance they will receive unnecessary procedures or be admitted to the hospital (Greer et al., 2013).

In their cluster randomized controlled trial, Zimmerman et al. (2014) sought to assess the impact of early palliative care on various aspects of quality of life. Quality of life was assessed using the Functional Assessment of Chronic Illness Therapy- Spiritual Wellbeing (FACIT-Sp) and the quality of life at the end-of-life (QUAL-E). Symptom severity was assessed using the Edmonton Symptom Assessment System (ESAS), satisfaction with care was assessed using the family caregiver satisfaction of palliative care services scale (FAMCARE-P16), and problems with medical interactions was assessed using the Cancer Rehabilitation Evaluation System Medical Interaction Subscale (CARES-MIS). These assessments were conducted at baseline and monthly every four months.

Between December 1, 2006 and February 28, 2014, 461 patients from 24 medical oncology clinics at the Princess Margaret Cancer Centre in Toronto, Ontario, Canada were cluster randomized to either consultation and follow-up by a palliative care team or to standard oncology care. These patients had advanced cancer, a European Cooperative Oncology Group Score (ECOG) of 0-2 (indicating good performance status), and a prognosis of 6-24 months. Two hundred twenty eight patients were randomized to the intervention group and 233 to the control group. Those randomized to the interventions group—early introduction of palliative care—received monthly visits by a palliative care physician and palliative care RN. At every visit, patients received a structured physical and symptom assessment; discussed goals of care, support needs, coping and psychosocial distress; and discussed advanced care planning if the patient was ready and willing. Each patient received a follow-up phone call after every visit by a palliative care RN and had access to a 24-hour on-call palliative care service.

Those randomized to the control group received standard oncology care, which consisted of visits with their oncologist or oncology RN ad hoc, mostly around chemotherapy or radiation treatment visits. This group did not receive routine assessment of physical, social, emotional, or spiritual wellbeing nor did they receive any follow-up phone calls unless necessary for logistical reasons or if receiving a return phone call. This group did have access to a 24-hour oncology telephone service, staffed by an oncology resident or other oncology clinician. These patients could also receive a palliative care consult by request (Zimmerman et al., 2014).

There was a significant difference between the control and intervention group on the QUAL-E ($p = 0.05$) and FAMCARE-P16 ($p = 0.0003$) at three months, indicating patients in the intervention group experienced greater quality of life at the end-of-life and had enhanced family caregiver satisfaction than those receiving standard care. At four months, patients in the intervention group had higher scores on the FACIT-Sp, QUAL-E, and FAMCARE-P16, representing greater quality of life and satisfaction with care. ESAS scores were less than the control group, indicating better symptom control. There was no significant difference between scores on the CARES-MIS between groups. Although not without limitations, the findings from this study favor the integration of palliative care services with standard oncology care in improving quality of life and satisfaction with care for patients with advanced cancers.

Symptom prevalence. The Institute of Medicine (IOM, 2001) report *Improving Palliative Care for Cancer* brought awareness to the role of palliative care as a mechanism toward better management of complex symptoms and psychosocial issues, and called for improved access to palliative care services. In accordance with this call to action, Teunissen et al. (2007) sought to provide insight for clinicians who care for patients with advanced cancer. They conducted a systematic review evaluating symptom prevalence among a large, heterogeneous

population of patients with incurable cancer. MEDLINE, EMBASE, and CINAHL were reviewed and a total of 46 studies met inclusion criteria. The authors divided the studies into two different groups: Group 1 consisted of 40 studies (25,074 patients) assessing overall symptom prevalence, and Group 2 contained two studies (2,219 patients) which focused on symptom burden in the last one to two weeks of life. Each symptom was defined by the authors, incorporating synonyms, as there was no consistent terminology across studies. Q-tests indicated a high level of heterogeneity among the studies, one limitation of their review.

Thirty-seven symptoms were identified and found to affect more than 10 % of patients. 'Fatigue', 'pain', 'lack of energy', 'weakness', and 'loss of appetite' were the most common symptoms, occurring in more than 50% of patients in Group 1. The most significant finding, and consequent limitation, was the inconsistency among symptom assessment methods, which led to varying degrees of symptom prevalence responses. Teunissen et al. (2007) recommend utilizing a standardized comprehensive assessment tool, such as a questionnaire, to further capture the true essence of symptom burden among these patients.

Palliative care consultation. Follwell et al. (2009) inadvertently carried out the recommendation by Bakitas et al. (2009) in their Phase II prospective cohort study by seeking to discover the value of palliative care consultation on symptom pervasiveness and patient satisfaction. Over the course of nine months, 150 eligible patients were recruited during their first visit to the Oncology Palliative Care Clinic (OPCC) at Princess Margaret Hospital in Toronto, Ontario, Canada. At baseline, patients completed the ESAS and the Family Satisfaction with Advanced Cancer Care (FAMCARE) scale (Kristjanson, 1993). The primary consultation lasted 90-120 minutes and included a full history, physical, and psychosocial assessment, from

which recommendations for comprehensive supportive care were made on an individual patient basis.

There was a fairly even distribution of male to female participants (51% vs. 49%, respectively) with a wide variety of tumor types, and a majority of patients with an Eastern Cooperative Oncology Group (ECOG) score of 1 or 2. At baseline, the mean ESAS score was 39.5 and the mean baseline FAMCARE score was 34.7. The ESAS score is obtained from the summation of the individual scores on each of the nine items, with a total range from zero to 90. The lower the score, the lesser the symptom distress (Zimmerman et al., 2014). The items on the FAMCARE scale are given on a 5-point Likert scale with one corresponding to very satisfied and five corresponding to very dissatisfied. The total possible points are 100; thus, the higher the number the more dissatisfied the individual (Rodriguez, Bayliss, Jaffe, Zickmund, & Sevick, 2010).

Patients were followed up by phone at one week and one month after their initial PC visit, each time the ESAS and FAMCARE scale were re-administered. At one-week follow-up (n = 123), there was an overall improvement in the ESAS score by a mean of 8.8 points ($P < .0001$; clinical efficacy was evaluated by an improvement in ESAS score by at least one and occurring in a minimum of 40% of patients for that symptom). There was also demonstrable improvement in ESAS scores at one month ($P < .0001$), with significant improvement reported in anxiety, insomnia, dyspnea, depression, and pain. However, there was a substantial decline in patient participation (n = 88) introducing the threat of bias into the study, suggesting that the patients who remained were likely to have better outcomes.

There were also improvements in FAMCARE scores at both one week and one month ($P < .0001$ and $P = .0002$, respectively). More specifically, improvement in the domains of

information given about how to manage pain, *doctor's attention to symptoms*, *pain relief*, *how thoroughly the doctor assesses symptoms*, and *speed with which symptoms are treated*, were all found to be statistically significant ($P < .0001$). These domains represent core values of palliative care and while it is unrealistic to expect to see relief of every symptom or improvement in each satisfaction category, these results demonstrate clinically significant outcomes specifically influenced by palliative care expert intervention (Follwell et al., 2009).

Palliative care assessment tools. In addition to demonstrating the importance of incorporating palliative care alongside cancer care early on in the disease process, the question of how to do so remains unanswered. Bausewein, Grice, Simon, and Higginson (2011) conducted a systematic review to assess how the Palliative Care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) have been used, and to identify their respective strengths and weaknesses. MEDLINE, EMBASE, PsycINFO, British Nursing Index and Archive, and CINAHL databases were searched, yielding 159 papers, 83 of which were included in the review (39 on STAS and 43 on POS). The STAS tool was created in 1986 to distinguish the work of palliative care teams and was designed for use by a provider caring for the patient. The POS grew out of the STAS 13 years later to incorporate a subjective component, allowing the patient to rate their physical, emotional, psychosocial, and spiritual symptoms as well as their information and resource needs.

Each study was evaluated and data aggregated for year of publication, author(s), location/country, study participants, purpose of chosen outcome measure, data collection methods, study focus, and results (Bausewein et al., 2011). Findings from this review are unimpressive and immaterial. Eight STAS studies validated the original version of the tool; four of the studies used an adapted version. Twenty studies used the STAS in another culture and 19

papers used the tool in another language. Findings revealed 14 adapted versions of the POS, 12 translations, and 15 studies utilized the tool in languages other than English. While these tools were intended for use with palliative care patients, various study authors extended both the STAS and POS for use among patients with HIV/AIDs, neurologic disease, chronic obstructive pulmonary disorder, congestive heart failure, and chronic kidney disease. Furthermore, these tools have been implemented in various healthcare settings, among formal and informal caregivers, translated into several languages, and used around the world (Bausewein et al., 2011).

Although the utilization of these tools has expanded remarkably over the years, there are more limitations than strengths of this review (Bausewein et al., 2011). There is a significant threat of bias as the first author developed STAS and POS, and the last author has validated a translated version of the POS. Secondly, there is poor generalizability of findings as the studies reviewed were heterogeneous and rigorous statistical analysis was absent. Moreover, there were no conclusive findings, and observations did not lead to direct implications for practice. This review further emphasizes the need for standardization of outcome measures and suggests a universal toolkit of processes and evaluation tools in the provision of care (Bausewein et al., 2011).

Brasel (2007) introduces several screening tools and discusses the importance of selecting the tool that will most accurately assess for specific outcome(s) of interest. She reviewed the Karnofsky Performance Scale (KPS), the Edmonton Symptom Assessment Scale (ESAS), the Memorial Symptom Assessment Scale (MSAS), the Quality and Quantity of Life Questionnaire, the Cambridge Palliative Assessment Schedule (CAMPAS-R), and the Palliative Outcome Surgery Score. Brasel provided a brief description of each tool and explained its application in practice. While this list is not comprehensive, it highlights the role of each of these screening

tools in palliative care practice. Furthermore, Brasel reviewed the usefulness of screening tools as an objective way to estimate prognosis, to reduce the potential for clinician bias to influence patients and their caregivers when considering patient goals and desire for treatment, and to assist in monitoring progress and evaluating efficacy of practice.

Although they did not endorse specific assessment tools, the National Institutes of Health State-of-the-Science panel (NIH, 2004) convened in July 2002 to discuss ways to improve awareness of cancer-related symptom burden and increase involvement in combating its negative impact on QOL, particularly addressing pain, depression, and fatigue. This 14-member panel of oncology, radiology, psychology, nursing, social work, public health, and epidemiology concluded that routine screenings using brief assessment tools should be employed to better provide evidence-based care. Furthermore, the panel advocated for these assessment measures to serve as catalysts for initial and ongoing discussions throughout the course of the illness. Lastly, they recommended visual analog scale (VAS) or numeric rating scales to be the framework for these chosen assessment tools.

Richards et al. (2011) observed a gap in assessment of palliative care needs and care directed towards these needs in the ED. As a solution to help cancer patients better communicate their complex palliative care needs to ED providers, and in hopes of facilitating care according to specific need(s), 12 ED clinicians developed and implemented a multidimensional palliative care assessment tool for cancer patients who present to the ED, Screening for Palliative Care Needs in the ED (SPEED). Each of these clinicians had training in Education in Palliative and End-Of-Life (EOL) Care (EPEC). Each question on the SPEED instrument was individually matched to similar questions on other validated screening tools, totaling 3,011 questions from 86 identified symptom assessment tools. Their aim was to evaluate the validity and reliability of this screening

tool against these other standardized assessment tools. After extensive analysis, the SPEED tool was found to be effective and valid in screening for palliative care needs in the ED.

Browner and Smith (2013) sought to identify *gerocentric* assessment tool metrics to capture the true complexity of cancer needs in the elderly population. They recognized it is not only crucial to intervene when symptom burden is present, but it is imperative to consider the spectrum of palliative care needs in the elderly. They briefly discussed the span of symptoms known to plague geriatric patients, such as neuropathic pain, depression, and diminished physical functioning. The five screening tools they highlighted were the Memorial Symptom Assessment Scale (MSAS), the Condensed Memorial Symptom Assessment Scale (MSAS-C), the Edmonton Symptom Assessment Scale (ESAS), the MD Anderson Symptom Inventory (MDASI), and the European Organization for Research and Treatment of Cancer's Quality of Life Core Questionnaire (EORTC QLQ-C30). In their practice, Browner and Smith use a Rounding Tool that stems from the MSAS-C that asks two questions specific to the reported symptom. With the implementation of this particular tool, they have demonstrated a reduction of symptoms in a cohort of patients. They concluded that while there are several validated and useful screenings, not one is explicit to the elderly population, nor is one all-inclusive. Browner and Smith further highlighted that many of the interventions used to treat younger patients are also effective in the elderly.

Is one screening tool better than another? Many of the reviewed articles sought to explore whether one screening tool outweighed another. Stro¨mgren, Groenvold, Pedersen, Olsen, and Sjogren (2002) recognized the array of symptoms cancer patients experience and the inability of one tool to accurately capture them all. The aim of their retrospective study was to (a) identify the most common symptoms that warranted a palliative medicine referral, and (b)

compare their findings with five validated and widely used questionnaires. The five tools evaluated included EORTC QLQ-C30, the ESAS, the Palliative Care Outcome Scale (POS), the McGill Quality of Life Questionnaire (MQOL), and MSAS. From their inclusion and exclusion criteria, these authors identified 171 eligible inpatient adults. They did a chart review to identify individual patient's primary symptom(s) or problem(s). Stro¨mgren et al. used the symptoms list from the EORTC QLQ-C30 and the ESAS to build their symptom inventory. They found 63 problems/symptoms of which 35 were identified by one of the five comparative questionnaires. Additionally, these authors found that the EORTC QLQ-C30 and the ESAS collectively covered 12 of the most commonly identified problems in the medical record, concluding the EORTC QLQ-C30 to be the better comprehensive screening tool because it is more generalizable to different cancer populations and used validated psychometric properties,

In their prospective, cross-sectional study, Schultheis, Hofheinz, Gencer, Blunk, and Benrath (2013) set out to determine how to best evaluate QOL among patients undergoing chemotherapy for a gastrointestinal (GI) malignancy. They employed the EORTC QLQ-C30, Beck depression inventory (BDI), and the VAS for assessment of pain in 150 patients. Low scores on the BDI and VAS were predictive of poor results in nearly all areas on the EORTC QLQ-C30 (indicating poor quality of life). Like Stro¨mgren et al. (2002), these authors also found the EORTC QLQ-C30 adequately incorporated the assessment of pain and depression, and could be considered as a single all-inclusive assessment tool. An additional advantage identified was its ability to be converted to an electronic version and distributed via the Internet or on hand-held devices (Schultheis et al., 2013).

Pelayo-Alvarez, Perez-Hoyos, and Agra-Varela (2013) also conducted a comparative study between the POS, Brief Pain Index (BPI), and Rotterdam Symptom Checklist (RSCL) to

evaluate the reliability and criterion validity of the POS as the concurrent validity among similar domains in the RSCL and BPI. Analytical findings indicated concurrent validity of the POS only with the physical domain on the RCSL. However, the pain domain on the BPI is interchangeable with the pain and physical domains of the RCSL. Nevertheless, these tools are not interchangeable and the POS cannot be substituted with the BPI or RCSL and obtain the same outcome measures (Pelayo-Alvarez et al., 2013).

Bush et al. (2010) also advocate for a standardized way to assess QOL in cancer patients, yet recognize the difficulty in accomplishing this given the large and varying symptoms experienced. Thus, the authors conducted a retrospective study to explore the relationship between the single-item ESAS and the multidimensional Functional Assessment of Cancer Therapy-General (FACT-G), specifically the "feeling of well being" (ESAS WB), and family well being (FWB), but did not include the social well being (SWB) domain. No conclusive statements or implications for practice were recommended. Interestingly, the authors divulged that they use the Functional Assessment of Chronic Illness Therapy Fatigue (FACIT-F) and the Functional Assessment of Anorexia/Cachexia Treatment (FAACT) in their daily practices (Bush et al., 2010).

Screening for distress. In a randomized control trial, Carlson, Waller, Groff, Zhong, and Bultz (2012) screened all eligible patients through kiosks located in the clinic, then randomized patients to receive either computer-based triage or personalized triage. The computer-based triage group was the control group. Once patients completed their screening at the kiosk, a report was generated, printed, and recommended services were outlined based on the patient-specific responses. Services included psychosocial support, resource counseling, pain, fatigue, and nutrition management services. The patients then determined if they would benefit

from any one or more of the services, and thus would self-refer.

The personalized triage group participants would also complete their screening at the kiosk and receive a printed report however, they would be contacted via a telephone call by a psychosocial healthcare professional within three days of completing the screening. The healthcare professional would then review the same options given to the computerized triage group, and put in a referral(s) based on the professional's clinical judgment. A total of 3,133 patients provided baseline data with 1,709 patients remaining at the end of 12 months. Follow-up was made via phone or email at three, six, and 12 months after initial screening (Carlson et al., 2012).

The primary objective of this study was to evaluate whether there were any changes between groups in regards to distress, anxiety, depression, pain, and/or fatigue over the course of the 12-month study period (Carlson et al., 2012). Surprisingly, the authors did not observe any differences between groups; both groups experienced decreases in each of the five categories. An interesting distinction was seen in the group who received personalized triage: this group accessed more services than the computerized group (1,213 services versus 825 services). However, all patients who used services demonstrated greater improvement of symptoms overtime, but were more anxious, depressed, and had more distress at baseline (Carlson et al., 2012).

This study demonstrates the efficacy of the provision of resources on improving outcomes in addition to screening (Carlson et al., 2012). The ultimate takeaway from this study is the importance of comprehensive assessment and management of symptoms once they are identified through screening to achieve the most positive outcomes and provide the most benefit to the patient. The authors suggest that personalized triage may provide greater benefit to

patients with high anxiety and depression as these patients were more likely to use the available services. Nevertheless, both methods of triage were effective in managing symptoms (Carlson et al., 2012).

Also recognizing the importance of screening patients for palliative care needs, Paul Glare and his colleagues (2013) conducted a pilot study among patients with gastrointestinal (GI) malignancies to evaluate whether the NCCN Guidelines for Palliative Care were feasible to use for screening and generating palliative care (PC) referrals. Nurses screened all patients who were admitted to the 16th floor of Memorial Hospital of Memorial Sloan-Kettering Cancer Center between November 2010 and January 2011. All patients were screened for the presence of the six following PC concerns: uncontrolled symptoms, moderate-to-severe distress, serious comorbid illness, a poor prognosis, patient/family concerns about the course of the disease and the treatment decision-making, and patient/family requests for PC. A *positive screening* was defined as any patient meeting one or more of the clinical situations mentioned above. The GI Oncology service was broken into two teams for the purposes of this project, Team A and Team B. The NCCN PC Guidelines' referral criteria were only applied to Team A; if a patient met one of the 24 referral criteria, the physician would place a PC consult. Any patient on Team B could receive a PC consult, but this was ordered ad hoc by the physician based on his/her clinical judgment (Glare et al., 2013).

Over the course of the three-month project, 90% of patients were screened (n = 254). Seventy three percent of patients on Team A (n = 229) had positive screenings, 87 from Team A and 83 from Team B; there were no significant characteristic differences between Team A and Team B. Uncontrolled symptoms was the most commonly reported problem, followed by serious comorbid disease and a poor prognosis. Fifteen percent of patients reported distress related to

their cancer diagnosis or its treatment and decision-making concerns. Sixty four percent of patients on Team A met referral criteria; the median number of positive referral criteria met per patient was 1.5 (range, 1-11). Sixty- two out of 229 patients (27%) received PC consultations as a result of this study, 47 from Team A and 15 from Team B ($p < .0001$). This indicates a significant increase in access to PC. An additional finding of this study was that these referrals occurred earlier in the course of disease for patients on Team A (Glare et al., 2013).

Sixteen nurses were surveyed for their feedback and a majority of the respondents found the screening to be simple and quick and did not significantly impact their workload (Glare et al., 2013). However, several respondents reported they did not feel screening notably improved patient care, and furthermore, they did not feel they knew the patient well enough to screen them accurately. An additional component of this study was the development of a matrix to identify the complexity of PC needs and indicate whether they could be managed by the patient's oncology team (primary or generalist level palliative care) or whether they require management by a specialist PC team. Thirty percent of patients were identified to have PC needs that could be addressed and managed by their oncology team, at the generalist level (Glare et al., 2013).

Through this study, Glare and colleagues (2013) demonstrated how screening for distress helps identify PC needs earlier and is an important component of cancer care, regardless of disease stage. Fifty percent of patients with early stage disease or no disease screened positive due to comorbid illness, poor performance status, and/or had uncontrolled symptoms. While this study has many limitations, it remains one of the few studies conducted evaluating the role of screening in improving access to PC services. In addition, it highlights the need for more palliative care education for primary oncology team clinicians (Glare et al., 2013).

The role of screening tools in measuring outcomes. Dudgeon et al. (2008) conducted an evaluation study in which they employed a variety of interventions and conducted pre- and post-study surveys to determine how the practice changes implemented affected the management of symptoms in cancer patients, caregiver burden, and overall satisfaction of care. The practice changes developed for the purpose of this study involved an extensive multidisciplinary care team and consisted of using standardized screening tools, consensus-based collaborative care plans (CCPs), and guidelines for symptom management to improve responsiveness of the system to meet patient and caregiver needs. Outcome measures included the number of emergency department (ED) visits; inpatient hospital admissions; hospital lengths of stay; number of referrals to both outpatient and inpatient palliative care programs; and time enrolled in a home, long-term care facility, and palliative care units until death (Dudgeon et al., 2008).

The ESAS tool was administered to eligible patients in November 2002 and November 2003. The Family Satisfaction with Advanced Cancer Care (FAMCARE) instrument was used to measure caregiver and patient satisfaction with palliative care, and was administered in November 2002 and November 2003. Lastly, the caregiver reaction assessment (CRA), which assesses caregiver burden, was administered to caregivers in November 2002 and November 2003 (Dudgeon et al., 2008).

A chart review of two cohorts of participants, both including patients and caregivers, was used for data analysis and evaluation of interventions (Dudgeon et al., 2008). The findings demonstrated an improvement in symptom documentation, most significantly in pain documentation ($p < .001$), and a decrease in all mean symptom scores on the ESAS (indicating improvement) except for depression. These findings, however, were not deemed statistically significant ($p = 0.121 - 0.914$), but could still be considered clinically significant (Dudgeon et al.,

2008). There was no significant improvement in satisfaction related to care among caregivers or patients, nor was there a difference in caregiver burden between 2002 and 2003. Administrative outcomes revealed a reduction in the number of visits made to the ED, fewer inpatient hospital admissions, and a decrease in deaths in the acute care setting (Dudgeon et al., 2008).

The acknowledgment of invasive symptom prevalence among cancer patients initiated a discussion about what to do when symptoms are identified (Browner & Smith, 2013). Seow, Sussman, Martelli-Reid, Pond, and Bainbridge (2010) examined whether patients who reported greater symptom burden, indicated by higher scores on symptom assessment measures, received superior symptom-specific intervention. To evaluate symptoms, the authors used an electronic form of the ESAS and conducted retrospective chart reviews of 912 breast and lung cancer patient visits noting documentation of symptom(s) and whether action was taken to address the identified symptom(s) within one week. The primary independent variables were pain and shortness of breath (SOB) and the outcome measure was action taken related to either symptom whether it was drug therapy, a referral, a test, or other treatment. Scores were categorized as none (0), mild (1-3), moderate (4-6), or severe (7-10).

Seow et al. (2010) found a greater correlation between *severe*-reported symptoms and documentation (48% for pain and 79% for SOB). However, this did not consistently correlate to enhanced documentation of actions taken related to the symptom; yet as the severity of symptoms worsened, clinicians were more likely to document the symptom and take action. The authors discussed the advantages and disadvantages of the use of a screening tool and recognized that it does not always lead to improved symptom management, but they believed it facilitated discussion of treatment plans and provided a consistent unit of measure for symptom monitoring. The findings also suggested more attention is needed to create clear clinical care pathways for

symptom intervention to better alleviate symptoms and lead to improved patient outcomes.

Kamal et al. (2013) pioneered their own electronic assessment tool, the Quality Data Collection Tool for Palliative Care (QDACT-PC), which measured the relationship between assessment of symptoms and patient outcomes. In this cross-sectional analysis they compiled 18 metrics taken from ASCO's Quality Oncology Practice Initiatives (QOPI); the Cancer Assessing Symptoms, Side Effects, and Indications of Supportive Treatment (ASSIST); and the Carolinas Center for Medical Excellence in Hospice: Prepare, Embrace, Attend, Communicate, and Empower (PEACE) project. Conformance was measured for each metric across 459 cancer patients. Assessment of comprehensive symptoms, including constipation and fatigue, and the timely management of reported symptoms were all highly positively correlated to greater QOL ($p < .05$) and emotional wellbeing ($p = .001$).

Additionally, a high performance status (measured by the Palliative Performance Scale [PPS]) was also predictive of high QOL ([OR], 5.21; $P = .003$). Though not without limitations, this study illustrates how to test conformance among quality measures and evaluate patient outcomes. While it does show 100% positive correlation of evaluable measures with QOL, this study does demonstrate the utilization of a screening tool to assist in more fully understanding patient needs and how interventions positively influence patient outcomes, specifically QOL. Kamal et al. (2013) also advocate for the development of care pathways to assist in standardizing palliative care to address specific needs and ultimately improve patient outcomes.

The influence of screening tools on clinical care pathways. Khatcheressian et al. (2005) advocate for better recognition of symptoms in cancer patients and the implementation of algorithms or clinical care pathways that will adequately address and monitor for change. These authors review the state of palliative care practice and serve as a resource for practical ways to

integrate the control of symptoms into patient care. The authors (who are palliative care experts from the Palliative Leadership Center) endorse both the ESAS and RSCL as appropriate symptom assessment measurements. The paper reviewed various studies that demonstrate improved outcomes in pain using pain assessment scales and algorithms as an example for the utility of assessment scales in practice. Furthermore, the correlation among improved symptom control and lower healthcare costs was examined. This paper also highlights the standard set forth by the Center to Advance Palliative Care (CAPC) that utilization of standardized, feasible, reliable, and valid assessment tools should be incorporated into daily practice. Additionally, Khatcheressian et al. briefly discuss how electronic triggers have the potential to aid physicians in improving palliative care assessments and more successfully integrating evidence-based practice guidelines into palliative care practice.

Cleeland et al. (2013) recognized that the purpose of symptom identification extends beyond palliation and serves to provide significant information to help clinicians deliver better cancer-specific care. For example, as a result of documented patient symptomology, pharmaceutical companies can better understand and potentially tailor drug therapy to the side effect profile identified through symptom assessment. This scenario speaks to the role of symptom analysis in clinical research, yet still does not address the lack of standardization of symptom measurement. In response to this gap, a group of interprofessionals from the Food and Drug Administration, National Cancer Institutes, pharmaceutical companies, researchers, and patient advocates convened to form a taskforce, Assessing the Symptoms of Cancer using Patient-Reported Outcomes (ASCPRO) (Cleeland et al., 2013).

The purpose of this taskforce was to review the current state of symptom measures in clinical research and make recommendations for improved utilization and implementation

(Cleeland et al., 2013). While they did not discuss specific measurement tests like Brasel (2007), they emphasized the need to assess multiple symptoms in an appropriate, valid, and reliable way. They also encouraged assessment on a case-by-case basis ensuring adequate and thorough assessment of symptoms that will reveal meaningful and useful information (Cleeland et al., 2013; see Appendix F for an evidence table of the RCTs included in this literature review; see Appendix G for a breakdown of levels of evidence of all the articles reviewed in this section).

Clinical Implications

In an attempt to operationalize and heed the recommendation from ASCO (Smith et al., 2012) and the NCCN (n.d.) to incorporate palliative care alongside cancer care early in the disease process, the articles reviewed have uncovered a common discrepancy: a lack of standardization of tools to assess the impact of palliative care and evaluate outcomes in an organized way. Furthermore, a resounding endorsement for a specific symptom assessment tool to use is lacking despite the significant body of evidence supporting the value of screening tools in palliative care practice. A majority of the articles recommend similar characteristics such tools should possess.

Focusing on screening tools specific to emotional distress, Vodermaier, Linden, and Siu (2009) discuss general principles for the selection and application of such tools. The recommendation is for shorter-length tools for patients in the hospital or patients who are undergoing treatment. This is for the purpose of conserving patient energy as well as considers the feasibility of using a longer assessment tool in the acute care setting. On the other hand, they recommend a longer screening tool be administered to patients post-treatment or in the outpatient setting as these tools tend to more comprehensively capture patient needs. They advised for the

consideration of psychometric properties and encouraged tool length, treatment setting, and patient disease stage to ensure an appropriate tool selection (Vodermaier et al., 2009).

Advantages and disadvantages of screening tools. The following advantages were highlighted by various authors included in this review. Screening tools:

- allow for objective evaluation by the patient, family, and provider and highlight symptom control (Cleeland et al., 2013; Kamal et al., 2013; Brasel, 2007);
- aid in facilitating open discussion about met and unmet goals, as well as treatment plans and expectations (Schultheis et al., 2013; Bush et al., 2010);
- help predict prognosis and survival (Brasel, 2007);
- can be integrated into the electronic medical record and distributed via hand-held devices or touch screens (Schultheis et al., 2013; Seow et al., 2010);
- can improve symptom documentation (Seow et al., 2010; Dudgeon et al., 2008);
- foster better individual patient symptom assessment and individualized treatment (Cleeland et al., 2013; Kamal et al., 2013; Schultheis et al., 2013; Richards et al., 2011; Bush et al., 2010; Seow et al., 2010);
- provide a standard way in which to initially assess and monitor symptoms throughout the course of the cancer care trajectory (Pelayo-Alvarez et al., 2013; Schultheis et al., 2013; Bush et al., 2010; Vodermaier et al., 2009; Dudgeon et al., 2008; Katcheressian et al., 2007; NIH, 2004; Stro¨mgren et al., 2002);
- assist in early detection of symptoms and more quickly detect changes as they occur (Bush et al., 2010);
- help prioritize patient services and resources based on symptom prevalence and severity (Carlson et al., 2012).

The review also highlights the disadvantages of screening tools**.** The disadvantages include the following:

- those who are sicker may not be able to use assessment tools and the lower response rates from this patient population skews information about these particular patient needs (NIH, 2004; Stro¨mgren et al., 2002; Hearn & Higginson, 1999);
- no tool is completely comprehensive, thus there is the chance for certain symptoms not to be offered or addressed (Bourbonnais, Perreault, & Bouvette, 2004).

Theoretical/Conceptual Framework

Given that cancer is now considered a chronic disease (Centers for Disease Control and Prevention [CDC], 2014), it seems appropriate and perhaps innovative to employ the well-known, well-published, and widely implemented Chronic Care Model as the conceptual framework for this project (McLellan et al., 2014; Tu et al., 2013; Coleman, Austin, Brach, & Wagner, 2009; Hung et al., 2007; Wasson, Godfrey, Nelson, Johnson & Batalden, 2007; Parchman, Zeber, Romero, & Pugh, 2007; Vargas et al., 2007; Homer et al., 2005; Bodenheimer, Wagner, & Grumbach, 2002). This model attributes its success in high-quality chronic disease management to ensuring a comprehensive interwoven system is in place to address and anticipate the plethora of needs that accompany a chronic illness. In order to best satisfy these needs, Dr. Wagner and colleagues from the MaColl Center for Healthcare Innovation identified six elements crucial to the successful delivery of chronic disease care: health system, delivery system design, decision support, clinical information systems, self-management support, and the community. Together, these elements make up the chronic care model (Improving Chronic Illness Care [ICIC], 2014).

The elements of primary focus for the purposes of this project are delivery system design, decision support, and self-management support, although there will be some attention paid to clinical information systems. The health system element—which focuses on the importance of gaining recognition, permission, and support from key stakeholders for program success and sustainability—was fortunately established prior to starting this project and was, in fact, the catalyst for the development of this project. The community element emphasizes the importance of partnering with outside organizations for long-term disease control (ICIC, 2014). While a vital strategic component of this model, this element is outside of the scope of this project.

The delivery system design element of the Chronic Care Model is at the core of this project as it is within this element that the project is operationalized. This element distinguishes the significance of effective and efficient patient-centered coordinated care, which the review of the literature indicates is lacking in the provision of cancer care, and therefore delivery system design embodies the primary goal of this project. In addition, this element aligns well the integrated care model, a framework that encourages direct collaboration between the primary oncologist and the palliative care team at the point of diagnosis (Bruera & Hui, 2012). Through decision support, applying evidence-based clinical guidelines into daily practice, and self-management support that empowers patients to take ownership of their health and wellbeing, cancer patients can receive appropriate individualized care (ICIC, 2014).

While many institutions and organizations are working to provide symptom assessment and psychosocial distress screening earlier for patients diagnosed with cancer, there remains a question on how best to do this. Many experts recommend an integrated model of palliative care provided concurrently with standard oncology care (Greer et al., 2013; Hui & Bruera, 2013; Smith et al., 2012; Edgren, 2008). In the few studies that have measured outcomes when

palliative care is integrated into oncology care, findings reveal these patients to have greater satisfaction, improved quality of life, and better mood (Zimmerman, Swami, & Krzyzanowska, 2014; Temel et al., 2010; Follwell et al., 2009).

Integration of palliative care into cancer care can take many forms depending on the setting, clinical practice, and infrastructure. This quality improvement project aligns with what Hui and Bruera (2013) identify as the *provider-based model*, which empowers oncologists to provide *primary palliative care* to their patients, to the extent of their clinical expertise, comfort, and bandwidth. Patients with more complex or severe needs are then referred to *secondary palliative care*, which consists of specialty palliative care clinicians who meet with patients separate from their oncologists and support them physically, emotionally, psychosocially, and/or spiritually for as long as necessary. *Tertiary palliative care* refers to the provision of palliative care by an inpatient palliative care team who provides support and care for patients with complex needs who are hospitalized. This model leaves the provision of both primary and secondary palliative care to the discretion of the primary oncology team, leaving much variability in the referral, utilization, and subsequent need for secondary and tertiary palliative care (Hui & Bruera, 2013).

The future state of this quality improvement project will incorporate aspects of the *systems-based model* (Hui & Bruera, 2013). In this model, there is a standard set of criteria patients must meet to receive a referral for palliative care services. This is in effort to streamline the referral process in order to provide every patient with the same opportunity to access these services, and thus not be dependent on an oncologist. In the next phase of this project, the hope is to alert the clinicians to *relevant answers* when they open the patient's chart, as well as to automate referrals to supportive care services based on PROMIS questionnaire responses.

Currently, RNs, advanced practice providers (APPs), and physicians can identify if patients have *relevant answers* by a red exclamation mark next to the questionnaire, but they need to access the questionnaire in order to see this. The goal of integration, no matter the model, is to optimize patient access to supportive care and to enhance the quality of life of both patients and caregivers through enhanced coordination of care among healthcare providers and the provision of timely access to supportive care and resources.

Section III: Methods

Ethical Issues

This project was deemed an evidence-based practice quality improvement project by the University of San Francisco Doctor of Nursing Practice faculty, and thus exempt from the Institutional Review Board for the Protection of Human Subjects (Appendix H). No identifying patient information was used and all rules and regulations identified by the Health Insurance Portability and Accountability Act (HIPAA) were upheld. Each team member involved went through an online module about patient confidentiality and HIPAA developed by SHC.

Ethical principles. This project serves to promote the ethical principles of beneficence, respect for autonomy, and to a certain degree, justice. At the heart of this project is the desire to do what is good (beneficence) for every patient with cancer who walks through the doors of SCI. This sentiment is operationalized through screening for distressing symptoms and psychosocial needs. If providers can more readily identify patients' needs early on in their diagnosis, then they can provide the patients with resources, improve their quality of life, and better support them throughout their cancer care trajectory. As much of the literature supports, cancer care is more than just treatment of the disease; it is whole person care and encompasses care for the physical, spiritual, psychosocial, and emotional domains (Greer et al., 2013; IOM, 2008; Jacobsen &

Wagner, 212; Meier, 2011; Ristevski et al., 2011; Smith et al., 2012). Furthermore, screening for comprehensive care needs allows providers to individualize care and maximize beneficence for each patient (Rainbow, 2002).

This project also upholds the principle of autonomy by facilitating patient empowerment. With screening comes improved identification of needs, which leads to more personalized discussions about how best to meet patients' needs with respect to their goals and values. Providing whole-person care allows for the patient to choose what resources/services/treatment modalities work best for them and most positively contribute to their quality of life. Patients also have the choice not to complete the screening, also respecting patient autonomy (Rainbow, 2002).

Lastly, the principle of justice is illuminated by this project as screening all cancer patients—regardless of their cancer diagnosis, age, demographic, or socioeconomic status—ensures equal opportunity for all cancer patients to participate and potentially benefit from better need identification and management. Subsequently, access to supportive care services is available to all patients, not just those who complete screening; however, those who complete screening are more likely to gain earlier access to these services. Nevertheless, this project casts a net wide in the hope of reaching all patients and improving their quality of life through early identification of needs and improved management of those needs (Rainbow, 2002).

Planning the Intervention

The intervention. The findings of an extensive gap analysis, the results from small tests of change and pilot projects, and responding to QOPI's accreditation guidelines requiring screening cancer patients for distress and wellbeing solidified SCI's commitment to this evidence-based practice quality improvement project. At the foundation of this project lies the

primary intervention: the implementation of an electronic screening tool to assess for comprehensive cancer patient needs. The PROMIS global screen was the assessment tool chosen for use SCI-center wide. The planning for this project took place in three phases.

Phase one: Selecting a screening tool. In the fall of 2013, Dr. Kavitha Ramchandran, a thoracic oncologist and Director of Outpatient Palliative Medicine at SHC, was approached by the Vice President and Director of SCI Operations and asked to select a screening tool that could be used to screen patients for palliative care needs throughout their cancer care experience. Dr. Ramchandran then asked this author—a doctoral student who is a seasoned hematology/oncology nurse with a passion for palliative care—to partner with her to fulfill this request. This author conducted a review of the literature to determine if one standardized, validated, comprehensive screening tool existed for the purpose of assessing palliative care specific needs (e.g., physical, social, emotional, and spiritual wellbeing).

The search concluded there was no one tool that was recommended over another; however, five tools were identified as being most popular for use among palliative care patients: the European Organization for Research and Treatment of Cancer's Quality of Life Core Questionnaire (EORTC QLQ-C30); the Edmonton Symptom Assessment Scale (ESAS); the Memorial Symptom Assessment Scale (MSAS); the Palliative Care Outcome Scale (POS); and the Rotterdam Symptom Checklist (RSCL). Although each of these tools has been employed in the palliative care setting, the POS is the only tool that was originally designed and implemented specifically for use in palliative care.

Without any true analysis, the POS was chosen for its broad assessment of symptoms including physical, psychological, emotional, and spiritual symptoms, as well as information and support needs. The POS is a validated instrument that was developed in 1999 and has been used

in a variety of settings: home, hospital, hospice, or nursing home (Bausewein, Daveson, Benalia, Simon, & Higginson, n.d.). It is a ten-item measurement tool and is informally endorsed by Center to Advance Palliative Care (CAPC). The overall profile score is the sum of the scores from each of the ten questions; therefore, the overall profile score can range from zero to 40. The total POS score is useful in understanding the broad picture, whereas individual scores such as pain and depression can also give important information on key aspects of the patient's situation (Bausewein et al., n.d.).

Dr. Ramchandran and this author initially piloted the POS in the Gynecologic Oncology outpatient clinic with one RN over 90 days between June 2014 and September 2014. Screening with the POS was done by a Multidisciplinary Care Coordinator (MCC), an RN whose job responsibilities include initial intake of patients over the phone, helping patients and families navigate through the Stanford healthcare system, and assisting them when they make subsequent visits to the clinic. The POS screen was done by phone, prior to the patient's first visit with their treatment team. A process document was designed by Dr. Ramchandran and a palliative medicine (PM) social work colleague to assist the nurse in sounding more natural in administering the screening while maintaining standardization of the screening process across all patients.

Beyond the initial training, workshops were conducted utilizing role-play methods as well as literature on therapeutic communication. Participants in the workshops were from different disciplines including a palliative medicine physician, a master's-prepared nurse that specializes in palliative medicine, an MBA-prepared hospital administrator, two bachelor's-prepared oncology nurses, this author, and a member of the Stanford Cancer Institute Patient and Family Advisory Council.

To complete the screening, the MCC followed a written script for the POS, tallied the score, and made a referral to palliative medicine based on a score of > 20. Dr. Ramchandran and this author compared the POS to the NCCN criteria for referral to palliative medicine. Patients were considered *positive* on the palliative care screen based on a score of 20/40 on the POS, a positive score on any one of the seven palliative care domains as designated by the NCCN guidelines (uncontrolled symptoms, moderate to severe distress, serious comorbid physical or psycho-social condition, life expectancy < 6 months, metastatic solid tumors, patient family concerns about decision making or course of care, and patient/ family requests for palliative care) (NCCN, n.d.)

Thirty-six patients were screened by the MCC. Thirty-three out of 36 completed the POS successfully during the initial intake call. Based on the screening criteria of a score of 20/40 on the POS, no patients met the criteria for referral to palliative care. Based on the NCCN criteria applied broadly (a positive for any single domain of the seven) 18 patients met the criteria. Ultimately two patients were referred to palliative care based on the clinical judgment of the MCC.

The primary challenges in the utilization of the POS were its administration over the phone and the timing of administration, which was early in the patient's relationship with the MCC. Based on feedback received from the MCC, it was difficult for her to deliver the screening in a natural way without losing the language and content of the screening. An additional significant barrier was the scoring system as no patients were screened into PM, leaving much of these decisions up to the MCC's clinical judgment and missing patients who would have benefited from PM early in the care continuum.

Based on the small pilot study in the Gynecologic Oncology clinic, Dr. Ramchandran and

the director of the survivorship program at SHC decided to change screening tools and use the Patient Reported Outcomes Measurement Information System (PROMIS) tool instead as it was already in SHC's repertoire. PROMIS is a validated and reliable tool developed by the National Institutes of Health (NIH, date) to capture patient reports of their physical, mental, and social wellbeing (Appendix I). The information gathered from this tool is intended to provide clinicians with patient insights as to the effects of treatment to enhance communication between patients and their healthcare professionals and to foster patient-centered treatment plans (NIH, n.d.).

Phase two: Design workshop. In February 2015, a multidisciplinary group of 25 patients, family members, oncology clinicians, and experts in patient experience and health services research convened to evaluate SHC's current state of PM and to formulate options for interventions. During this one-day workshop, small, multidisciplinary groups were formed and breakout sessions occurred throughout the day to provide space for participants to generate ideas for innovative models of cancer care. This working group identified five areas of focus for meeting patient and family needs and overcoming stated barriers: automated/standard processes for access to PM, education on primary PM, rapid reporting of outcomes of integration, relationship-building with referring clinicians, and improving access to primary and specialist palliative care resources. As a result, four interventions were developed and tested to address these, one of them being patient-reported outcome distress screening.

Phase three: PROMIS screening rollout. With momentum from the design workshop, this author along with Dr. Ramchandran, an evaluation specialist and biostatistician, a patient advocate who is the Chair of the Stanford Cancer Institute Patient Advisory Council, and a program designer/research assistant formed a team that would be responsible for operationalizing the PROMIS global screen to assess, monitor, and manage cancer patients' needs along their

cancer care trajectory. Over the next three months this interdisciplinary group met weekly for one to two hours with the overarching goal to redesign the cancer patient experience through greater access to palliative care services for those who need them. To achieve this goal, the design team focused on designing a standardized process to best identify and meet patients' supportive care needs, which we determined was early screening of patients' physical, social, emotional, and spiritual wellbeing. We developed a pilot project which we had planned to test in the Gynecologic Oncology clinics given that small tests of change had already taken place in this setting. From the plan-do-study-act (PDSA) cycles—a methodology for conducting tests of change by trial and evaluation (Institute for Health Improvement, 2015)—that would ensue, we would then develop our "ideal state" for screening and managing identified patient needs. This "ideal state" however, was unable to be actualized as the PROMIS screening tool was prematurely launched SCI-wide without any standardized processes in place.

Dr. Ramchandran was our project design team lead. The rest of the team members played specific roles according to their area(s) of expertise. We had a program designer/research assistant who prepared the agenda and visual documents for our meetings as well as immersed herself in all aspects of the project, creating relationships and forming professional alliances; our evaluation specialist helped develop our metrics, surveys, and evaluation measurements; our patient advocate offered the perspective of patients and their families and kept our focus on patients and family-centered care; and this author brought the perspective of a nurse leader and clinical expert in hematology/oncology nursing, along with her newly-acquired skills of evidence-based practice research and project planning.

Each of the team members had homework assignments to complete between meetings. This author focused on research and document development, which included:

- literature reviews;
- the development of an evidence-based practice algorithm for distress and symptom management (Appendix J);
- surveys for RNs (Appendix K) and medical assistants (Appendix L), for metric purposes;
- a one-page document explaining the purpose of PROMIS for healthcare professionals to reference (Appendix M);
- a gap analysis (Appendix D); and
- a Gantt chart for timeline purposes (Appendix N).

This author attended several meetings outside of our weekly design team meetings with other stakeholders and collaborative partners to inform others about the workings of our group, discuss the utilization and feasibility of PROMIS, and obtain feedback and suggestions for implementation strategies and staff support.

Communication among team members often took place over email or in person at either our weekly meetings or other meetings that were established on an as-needed basis. There was no formal communication matrix established among our design team members; however, the information from our meetings was disseminated to leadership and other key stakeholders in a hierarchical fashion (see Appendix O for the communication matrix). When needed, we invited various colleagues to our meetings for the purposes of sharing updates, collaborating on action items and next steps, and facilitating closed loop communication. Other collaborating members included the Integrative Cancer Care Program (ICCP) Service Center Operations Manager, Director of SCI Operations, oncology and palliative care social workers, specific Cancer Clinic

Program managers, psycho-oncology physicians and advanced practice providers, and additional patient and family advocates.

Once a month, Dr. Ramchandran and our program designer/research assistant would meet with the Vice President and Medical Director of SCI to discuss the current state of our project, make specific requests necessary for project completion, and further develop the idea for a central hub of supportive care resources. Additionally, once monthly they would meet with the Director of Cancer Center Operations to discuss our information technology (IT) infrastructure and support as well as operational logistics of PROMIS implementation and frontline staff support. Every Wednesday night, a large multidisciplinary group of clinicians made up of cancer supportive program leads, chaplaincy, SCI operations managers, and the Director of SCI Operations, would meet to discuss the current state of PROMIS, identify gaps, brainstorm practical and realistic interventions, and create the new model for patient and family cancer care experience, one centralized hub where every need will be triaged and referred to the appropriate supportive care service. These meetings also served as good "study" sessions in the PDSA cycle to report findings, gather feedback for continuous system improvement, and brainstorm next steps.

Cost/Benefit analysis. This project is funded by a generous donation of $500,000 and is a component of a larger SCI movement toward transforming cancer care to care that is more patient and family-centered. This endowment however, was given specifically to fund the design team budget and not the operations of our project. Moreover, this cost-benefit analysis includes only known operational costs and revenue pursuant to implementation of the PROMIS tool. Projected costs and revenue have been estimated for the first three years; year one includes all

non-recurring development and implementation costs, which are reduced in year two, and eliminated in year three.

Expenses. The project team consists of a group of seven individuals, a combination of paid employees and volunteers, and includes project and operational members. For the purpose of cost estimations, project team costs are expensed for a two-year period, after which time only operational members remain. Project team members include a Team Lead, a Program Designer/Research Assistant, the President of SHC's Patient and Family Advisory council, an Evaluation Specialist, a Clinical Informaticist, two Patient and Family Advisors, and this author. Operational team members include the ICCP Service Center Operations Manager, the Assistant to the ICCP Service Center Operations Manager, and Nurse Coordinator.

The Team Lead, a full-time paid employee of Stanford University, was/will be paid $30,000/$15,000/$0 across years one, two and three, respectively. The Program Designer/Research Assistant is a full-time employee who devoted 50% of her time to this project, at a cost of $25,000/$12,500/$0 across years one, two and three. The only paid patient representative is the President of SHC's Patient and Family Advisory council. About 30% of her time in this role is devoted to this team and project, which estimates annual costs of approximately $24,000/$12,000/$0. The Evaluation Specialist is a full-time employee of Stanford University and devotes about 25% of her time working on this project, with three year costs at approximately $31,250/$15,625/$0. The Clinical Informaticist (CI) was responsible for embedding PROMIS into the EHR, developing evaluation reports, testing, participating in meetings, and assisting to train the pertinent clinicians in its use. The CI spends approximately 5 hours per week (12.5% of his time) on PROMIS-related matters, estimating a total cost of

$9,375/$4,687.50/$0 in the first, second, and third years. The remaining three individuals—this author and two additional patient and family advisors—are volunteers.

Additional personnel expenses are for the Integrative Cancer Care Program (ICCP) Service Center Operations Manager, her assistant, and the Nurse Coordinator(s), accounting for the project's recurring operational expenses. Approximately 30% of the of the ICCP Service Center Operations manager's responsibilities is devoted to PROMIS, costing SCI approximately $33,000 annually. Additionally, 30% of the ICCP Service Center Operations manager's assistant's time is devoted to PROMIS-related duties, resulting in a cost of about $13,500 per year. It is estimated that 20% of the Nurse Coordinator's time will be allocated to the review questionnaires, and coordination of appropriate follow-up on identified needs, costing roughly $30,000 annually. Because patients are responsible for completing the PROMIS questionnaire, there is no additional expense for administering the tool.

An average of 4.45% of patients (n = 47) who complete PROMIS have *relevant answers* (see Appendix P). This could mean that approximately 50% of patients with *relevant answers* would be referred to social work or palliative care. Using this assumption as a constant for budgetary purposes, this means roughly 2.22% (n = 23.5 patients) completing the PROMIS tool will be referred to social work or palliative care, resulting in 11.5 new patient visits per month for social work, and 12 new patient visits per month for palliative care as a result of PROMIS.

Conservatively assuming that an average of 50% of these newly referred patients will require ongoing evaluation and management (E&M) services once monthly for three months, then at any given month during the year, the quantity of patients receiving established patient E&M services will be equivalent to those newly referred to social work and/or palliative care as a result of PROMIS. For example, if 12 patients are referred to palliative care in July, six of

these patients will require established patient E&M services in August and September. However, in August, a similar cohort of patients newly established in June (n = 12) will also require established patient E&M services, increasing the volume of established patients in palliative care to 12, in addition to the 12 new patient visits generated in August, for a total of 24 patients per month as a result of PROMIS referrals. This same logic is applicable to service line social workers as well.

Financially speaking, if there are a total of 144 new patient visits and 144 established patient visits annually to palliative care (based on the logic described above), the net costs to the institution would approximate $34,615 (see Appendix Q for cost/benefit analysis). This cost is the sum of the Palliative Care Physician and the Palliative Care Nurse Practitioner (NP) time spent in new and established patient visits as all patients receiving a palliative care consult and subsequent care are seen by a team of a Palliative physician and NP. Receiving the balance of new patient referrals—and providing the above outlined established patient follow-up services—service line social workers would conduct 138 new patient visits per year and 138 established patient visits per year. This results in a net cost to the institution of $8,846. Moreover, supportive care services personnel cost the organization a total of $43,462 as result of increased referrals to palliative care and social work (see Appendix Q for cost/benefit analysis).

Non-personnel expenses, including training supplies (i.e. copy paper, printer, printer ink, markers, snacks, T-shirts, and conference room use), outreach and marketing costs, and equipment and facilities, total an additional $3,500 annually. In sum, year one PROMIS related costs total $234,087. Year two costs are significantly reduced (the time devoted to PROMIS development and implementation is reduced by half), at $174,114. And finally, year three costs

exclude all development and implementation expenses from years one and two, resulting in a true operational budget of $114,302.

Profit. The revenue generated from PROMIS was calculated based on reimbursement rates for E&M services rendered by palliative care and social work. Therefore, the annual generated revenue from 144 new patient visits to palliative care is $46,800; annual revenue generated from 138 new patient visits to social work is $27,600. Total reimbursement for 144 established patient visits to palliative care is $28,080 and $16,560 for the 138 established patient visits to social work. These projections result in an estimated total annual revenue of $119,040 resultant from PROMIS-related services.

A few significant assumptions were made in the revenue calculation: (a) there will be no increase in the number of new and established patient visits per year to both supportive care services, (b) there will be no inflation in personnel salaries, and (c) there will be no increase in the reimbursable value of E&M services. The above analysis of the tangible costs and benefits of PROMIS implementation and ongoing use actually result in a net cost to SCI. Although there is a 26% reduction in costs in year two and additional 35% decrease in year three, these project-based implementation costs result in a $170,121 deficit after the first two years. However, a key point to note is that other relevant frames for analysis—such as the consumer frame, the insurer/payor frame, and the societal frame—would consider this project to have associated benefit in terms of overall healthcare resource utilization (Meier, 2011; Simeons et al., 2010).

Breakeven analysis. Assuming there is: (a) no increase in patients completing the PROMIS tool; (b) no increase in patients with *relevant answers* on PROMIS; (c) no increase in referrals to supportive care services; (d) no increase in new and/or established patient E&M services; (e) no increase in personnel wages; and, (f) no increase in reimbursement rates for

billable services, it is projected to take 38 years for the organization to break even (Appendix R). It is important to note this breakeven analysis excludes potentially relevant but less tangible benefits to the organization (e.g., reputational/marketing benefits, repeat customer benefits, prestige benefits [e.g., top talent attraction and retention], etc.).

Implementation of the Project

In June 2015, the collection of patient-reported outcomes (PRO) using the PROMIS global screen was launched electronically throughout SCI, which includes 12 cancer care programs (CCPs) encompassing 22 cancer clinics. The PROMIS screen was delivered to patients via their online health account three days prior to their first return patient visit. If not completed prior to this visit, the opportunity to complete it on the computer in the exam room while waiting for the physician was offered by the medical assistant. Once completed, PROMIS was sent electronically every 30 days thereafter. This author developed an algorithm to facilitate timely and efficient communication of patient care needs, as well as create standardized clinical care pathways to meet the identified need(s). This algorithm encompassed referrals to both primary and specialty cancer care services (e.g., oncology service line social work, psychological oncology, palliative medicine, and integrated medicine).

Beginning Monday morning, June 8, each medical assistant was instructed to identify whether or not the patient had filled out the PROMIS questionnaire. This author along with a small team comprised of the design team program designer/research assistant, the ICCP Clinical Operations Manager, and her administrative assistant, sat with every medical assistant and taught them how to add a specific column to their electronic medical record clinic view so that this would be easy to identify. We also taught them how to view completed questionnaires and how to assist patients in filling out the questionnaire electronically. We educated them on the purpose

of the PROMIS questionnaire and instructed them to notify the RN or APP is the patient had answered *fair* or *poor* to any of the questions, signifying *relevant answers* and thus needing follow-up.

We did this everyday for the first week of the PROMIS tool launch. Additionally, we circulated in every cancer care clinic providing additional support to RNs, APPs, and physicians also assisting them to incorporate the PROMIS questionnaire into their electronic medical record dashboard and also explaining in greater detail what the PROMIS tool is, its purpose and our intended use. We also informed these clinicians of the MA workflow and instructed the RNs and APPs to make referrals as they normally would, based on the indicated *relevant answers* from the PROMIS tool (Appendix S). Each day during the first two weeks of launching PROMIS, we would put up a large piece of white paper on a wall, outside of the clinics, where we created a parking lot of issues, feedback, and ideas. At the end of the day we would consolidate, summarize, and send out nightly reports from our design and implementation teams to the Director of Clinical Operations, all CCP managers, and the Vice President of SCI.

Planning the Study of the Intervention

Approximately 57% of Stanford cancer patients indicated that their health care team provided whole-person, compassionate care. Only 39% reported that their oncology teams asked about their physical, emotional, and social goals (n = 248). From patient interviews conducted by our design team, Oncology clinicians cited needing support in identifying and tracking holistic needs (E. Tribett, personal communication, September 16, 2015). Until June 8, 2015, there was no standard screening and tracking of distress at Stanford Cancer Institute (SCI). On June 8 a standard screening process using PROMIS global screen and referral algorithm for supportive services was implemented. Triggers were embedded into the electronic medical record to prompt

discussion of PROMIS and potential specialist support. The ultimate goal of this intervention was to regularly screen, assess and develop management plans for patient wellness in hopes of changing the conversation between patients, families, and providers to address impacts of cancer and its treatment on overall wellness.

Metrics. To effectively measure success, we developed metrics that were measurable with the ability to utilize electronic reporting through the EHR system. Our primary process measures included the following:

- number of patients who received a PROMIS questionnaire;
- number of patients who completed a PROMIS questionnaire;
- number of patients with identified needs (indicated by *relevant answers*, an answer of *fair* or *poor* on any one of the PROMIS questions);
- number of patients with identified needs that were addressed by their oncology team;
- number of patients with identified needs who were referred to supportive care services (specifically palliative care and social work for the purposes of this initial project phase);
- number of patients with identified needs who were seen by the consulting service.

In order to measure whether patients perceive a change in the conversation between them and their healthcare providers we plan to correlate Press Ganey scores as well as conduct additional patient surveys (which have already been instituted) to determine whether the care team asked about physical, emotional, social and spiritual goals; whether their treatment plan considered physical, emotional, social and spiritual goals; whether their care team explained how cancer and treatment would impact daily activities; and whether their care team delivered whole-person care.

Using the PDSA quality improvement design process we plan to run rapid cycles of evaluation every week for the first four weeks of implementation and at three months, six months, nine months, and one year. Additionally, we developed surveys for both RNs and medical assistants (MAs) to obtain qualitative feedback about the PROMIS tools' effectiveness and ease of use as one of our evaluation measures (Appendices K and L).

Critical milestones. While considered somewhat of a failure at the time, the inability of the Palliative Care Outcome Scale (POS) to screen patients into palliative medicine was a milestone as it gave us great insight into the needed education and training of the RNs to have discussions around palliative care needs, important characteristics of a screening tool, and the need for an electronic tool for ease of use and the ability to trend responses overtime, create reports for outcome evaluation purposes, and build in automated systems for alerts and referral algorithms. Another critical milestone was the publication of the Quality Oncology Practice Initiative (QOPI) guidelines (ASCO, n.d.) that require every patient to be screened for wellness by their second oncology visit in order to be an accredited cancer program. This guideline created a sense of urgency for project development and implementation as well as inducted leadership buy-in and partnership. This guideline also highlighted the importance of addressing palliative care needs and bringing whole-person care to the forefront of cancer care.

With the rollout of PROMIS also came a dedicated EHR support liaison whose primary responsibility was to assist with electronic report development and the creation of clinical decision support tools. The gift of this role to our team was significant as it allowed for feasibility of outcome evaluation and reporting functionality. Furthermore, this role solidified stakeholder buy-in as this person was directed to our team by SCI leadership and instructed to fulfill our requests for the purposes of information gathering and dissemination. In addition to IT

support, operational support was provided by the Director of Clinical Operations through a new role developed for the purposes of the Transformation Initiative: the Integrative Cancer Care Program Clinical Operations Manager. Part of this role's primary responsibility was to oversee the operational side of the PROMIS screening and partner with the design team on process improvement efforts.

Timeline. The timeline for this project spans almost two years. The beginning workings of this project first started in early 2014 and will continue into 2016. There were many project iterations that ensued over the course of this project timeline. This author's project prospectus was approved in December 2014, providing permission from USF and added support to assume a major leadership role in planning, implementing and evaluating the project (Appendix N).

Anticipated Outcomes

Given that prior to this project SHC had no universal form of standardized distress screening, the institution of a screening process SCI-wide is significant and its implementation alone provides substantial improvement from baseline data and meets the primary project goal: for all patients to be screened. Additionally, the information gathered from our chart review indicates that less than 20% of gynecologic patients were screened for distress; however, over 40% of patients had indications for distress that went unnoticed as a result of no formal screening process. Anticipated outcomes of this project include the following:

- improved coordination of care;
- enhanced abilities of patients and families to identify and articulate their needs and desires to their care teams;
- normalization of asking about patient well being for clinicians, patients, and families alike;

- enhanced attention to the dimensions of well-being during clinic visits and incorporation into treatment plans;
- more appropriate and timely access to support care services;
- developed standardized procedures and protocols for identification of patients in distress (i.e. with physical, psychological, emotional, or spiritual needs), referral criteria, and follow-up documentation;
- increased number of referrals to support services; and
- designated standard roles and trained personnel who hold referral responsibility.

Methods of Evaluation

A mixed method approach, using both qualitative and quantitative analysis, was employed to gather comprehensive evaluation information.

Quantitative. We will assess the percent of patients screening *positive* for distress, which is defined as any one answer of *fair* or *poor* on the PROMIS screen. If screened *positive* for distress, there will be a red exclamation mark next to the patient's questionnaire when viewed in the EHR. From this we will assess the rate of primary palliative care interventions. *Primary palliative care interventions* are defined as those interventions carried out by the patient's primary oncology team. We will also assess rate of referral to specialist palliative teams and social work (operationalization of this metric is still in process). Ideally, we would be able to have reports detailing the following information, which are essentially our metrics:

- number of return cancer patients who received PROMIS screening;
- number of return cancer patients who completed PROMIS;
- percent of return cancer patients who completed PROMIS;
- number of return cancer patients with identified needs via PROMIS;

- percentage of return cancer patients with identified needs via PROMIS;
- number of completed screens associated with a referral to social work and/or palliative care;
- percentage of completed screens associated with a referral to social work and/or palliative care;
- number of patients screened whose needs were not picked up by PROMIS, but who were referred to subspecialist services;
- percentage of patients screened whose needs were not picked up by PROMIS wellness survey, but who were referred to subspecialist services; and
- number of patients with identified needs managed by oncology team.

(see Appendix T anticipated outcomes paired with specific metric for evaluation).

Many of our objectives have yet to be met as we are still in the process of working with IT to create the desired reports electronically so that we can measure the above metrics. To date, the only metrics we have been able to implement are: the number and percent of patients who received PROMIS; the number and percent of patients who completed PROMIS; and the number and percent of patients with identified needs, otherwise known as *relevant answers* (see appendices P and W). Anecdotally, our social work colleagues are seeing an increase in referrals related to PROMIS. However, we do not have official data as we are in the midst of creating an electronic report through the EHR to specifically capture the number and percent of patients who are referred to social work and/or palliative care as a result of their PROMIS screen, as well as the number and percent of patients with relevant answers whose need(s) are addressed by their primary oncology team. If possible, we would like to further breakdown all referrals and analyze

them to also identify patients who do not screen *positive* by PROMIS who are still referred to specialist services, to better understand the breadth of patient needs.

In theory, these metrics work to meet our objectives of increasing access to supportive care services, ensuring the distribution, screening, and conversation around PROMIS is part of everyday practice, and that the process for evaluation, follow-up, and monitoring is streamlined. Depending on the results of our metrics, our team will have a better sense of whether our objectives are being fulfilled. For instance, if we obtain percentages on the number and percent of patients being referred to social work as a result of PROMIS, and it is significantly greater than the current referral rate, than we can infer that indeed patients are gaining access to supportive care services as a result of screening.

Qualitative. Both informal and formal qualitative methods of evaluation were used. During the first two weeks of implementation, support personnel were circulating in each of the CCP clinics and workrooms to answer questions and assist with tool utilization, while at the same time gathering real-time feedback on tool utilization, feasibility, and purposefulness. We put this feedback on a large sheet of paper we posted on the back wall of the clinic to inform others of our implementation processes and also helped serve as the *Study* component of the PDSA cycle. After the first two weeks, it became the responsibility of the ICCP Clinical Operations Manager and her administrative assistant to continue interviewing and circulating in the clinics and workrooms every week. At the end of the week, the ICCP Clinical Operations Manager sent out summaries of her findings and we would discuss modifications or changes at our design team meetings.

Additionally, this author created feedback surveys for both RNs and MAs (Appendices K & L) to obtain insight into the utility, feasibility, and applicability of the PROMIS tool to their

clinical practice. This author received both Dr. Ramchandran's and the evaluation specialist's approval prior to distributing this survey. The survey questions were reviewed by this author, the program designer/research assistant, and the evaluation specialist, all with content expertise. The survey consisted of Likert-type scale questions in which respondents indicated the phrase that best corresponded to their position on the asked question. There was also space after each question to free text comments. There was a total of ten questions on the RN survey and five questions on the MA survey.

The surveys were created in SurveyMonkey, an electronic survey development platform, and were sent electronically via email. The RN survey was sent out two months post PROMIS tool implementation. We plan to re-administer these surveys six months post implementation. The data received from these surveys were used to provide formative information for feedback loops for program improvement. We are in the process of collecting MA survey responses.

SWOT analysis. Implementation of an organizational-wide practice change will undoubtedly be met by skepticism, enthusiasm, disinterest, or pessimism. An analysis of the strengths, weaknesses, opportunities, and threats (SWOT) of incorporating palliative care into routine oncology care through the utilization of a standardized assessment tool (PROMIS) is an attempt to anticipate and identify strategies that will aide in the successful implementation and sustainability of this proposed practice change (Larson & Gray, 2014; see Appendix U for a detailed SWOT analysis).

Strengths. This project has many strengths, both on an operational and theoretical level. At the operational level, the implementation of screening at the second oncology visit and every 30 days thereafter provides earlier access to palliative care and supportive care services thereby integrating palliative care into routine oncology care, a national goal and new standard of

oncology care (Hui & Bruera, 2015; Smith et al., 2012; ASCO, n.d.; Lazenby, 2014; McNiff, Bonelli, & Jacobson, 2009). Screening patients for distress also encourages active participation on behalf of the patient in their plan of care, prompting the patient to share a problem(s) that might otherwise be overlooked or squelched (Bennett, Jensen, & Basch, 2012).

Furthermore, the utilization of electronic patient-reported outcomes (ePROs) aids in more efficient monitoring of patients' symptoms and treatment response over time, as well as monitors the effectiveness of interventions employed. Through electronic health record (EHR) alerts or clinical decision support tools, an ePROs system can also readily alert the clinician to needs identified through screening for prompt intervention, positively impacting patient management (Chen, Ou, & Hollis, 2013). This in turn enhances clinical workflow, increasing efficiency in patient care (Smith et al., 2014). The personnel for this project are either established employees or volunteers; therefore, no additional expenses were needed for the implementation of this project. SHC currently has a robust team of palliative care clinicians as well as disease-specific social workers available for supportive services referrals. Lastly, this project circumvents selection bias as screening is offered to all cancer patients, regardless of their disease type or stage, demographic or socioeconomic status.

Weaknesses. According to the gap analysis, many oncology clinicians do not feel adequately prepared to address supportive care needs and more specifically, psychosocial issues—this poses both a weakness and a threat for this project. It poses a weakness because the purpose of screening for distress is to identify areas of need. Once identified, this means having conversations with patients that many clinicians feel unprepared to have. This also poses a threat because if clinicians do not feel somewhat comfortable with having a potentially difficult

conversation, patients will not feel comfortable or safe engaging in conversation and may not view screening as useful.

Additionally, time constraints, charting responsibilities, patient volume, and a chaotic and busy environment all represent weaknesses as well as threats to the success of this project. Furthermore, there is no one screening tool that is identified as being superior to all the rest, nor are there specific guidelines detailing how to implement screening and clinical care pathways. Since there is no standardized algorithm for triaging screening responses, interpreting the clinical relevance of screening responses is somewhat left up to clinical judgment (Bennett, Jensen, & Basch, 2012). This can threaten the validity and reliability of the screening tool itself as well as the attempted standardization of clinical care pathways. Additionally, whether a patient receives a referral is at the discretion of the oncologist, potentially limiting a patient's access to services depending on the clinician. Lastly, PROMIS is only administered in English, excluding any non-English literate patient from participating. Future learning from this project will help identify what responses are clinically significant and whether or not to raise the threshold of what indicates a positive screen.

Opportunities. Stemming from this project are many opportunities for growth and development. From a project development standpoint, no studies to date have demonstrated the impact of PROs on quality improvement, transparency, accountability, public reporting, improved system performances, or impact on health outcomes (Chen, Ou, & Hollis, 2013). This project touches a few of these areas potentially allowing SHC to unveil some key findings that could provide greater insight into these areas of question. This project provides several opportunities: (a) to de-fragment care, (b) to enhance rapport among clinicians and patients as well as among interdisciplinary partnerships, (c) to improve symptom management thereby

improving QOL, (d) to change the culture and perceptions around palliative and psychosocial care, (e) to integrate palliative care into routine oncology clinical practice, (f) to facilitate more informed decision-making, and (g) to potentially achieve cost savings if less patients visit the ED or are admitted to the hospital due to poor symptom control.

The integration of an ePRO system for screening provides the opportunity to streamline clinician PRO review into their workflow (Bennett, Jensen, & Basch, 2012). The use of screening also provides meaningful information for patients, their caregivers, and clinicians (Wagner et al., 2015; Snyder, Jensen, Geller, Carducci, & Wu, 2010) and allows the opportunity for enhanced patient-provider communication (Chen, Ou, & Hollis, 2013; Carlson, Waller, Groft, Zhong, & Bultz, 2012). This project also serves to raise awareness to the importance of incorporating psychosocial care into medical care and improve clinical practice (Jacobsen & Wagner, 2012). Ultimately, this project has the opportunity to completely transform and standardize how we identify, evaluate, and manage physical, emotional, social, and spiritual needs.

Threats. As mentioned above, limited training in how to ask and respond to questions about distress poses a threat to both patient and clinician engagement, and could have a detrimental impact on patient perceptions of the usefulness of screening. Misconceptions about palliative care, its usefulness, impact, and importance also threaten the success of this project. Screening in any form can exclude patients with low literacy levels, language barriers, and visual or physical impairments (Pirl et al., 2014).

Budgetary return on investment. The year-one total expenses estimated for the implementation of PROMIS (which includes PROMIS personnel, supplies, and supportive care services personnel) is $234,087. The total annual revenue from reimbursements for palliative

care and service line social work for new and established patient visits is $119,040. This results in a return on investment of 51%. While this value indicates that while there were some positive financial benefits to this work, the return is not sufficient enough to recover implementation costs. However, because this project was funded by a private donation (of $500,000) there was no expectation of a profit. More important than any financial gain, screening (as a result of this project) has the potential to bring great value to patients through better and earlier identification of comprehensive care needs and prompt intervention of identified needs. Theoretically, such care can enhance quality of life through more effective care and management of symptoms and treatments, which provide invaluable benefit to the patient (see Appendix Q for further breakdown of profit/loss summary).

Analysis

Qualitative analytic methods. Self-report surveys were administered to every nurse coordinator, an outpatient RN who is responsible for an oncologist's patient population or a CCP, in SCI to get their initial feedback on the PROMIS questionnaire. This author, in collaboration with Dr. Ramchandran, the program designer, and the evaluation specialist developed a total of ten questions. The first nine questions were written with a corresponding Likert-type scale, where each response corresponds to a number from one to five with one indicating a poor or negative association and five indicating a positive or good association. The tenth question is an open-ended question in which participants were asked to mark all that apply. Every question provided a comment box for the participant to elaborate on their response or comment further.

The ten survey questions inquire about three categories: ease of use, utility (i.e. is PROMIS useful, relevant, and in alignment with patient needs), and training and development.

There were no comparisons or associations sought among RN responses nor were there computable means or standard deviations. This survey was developed for the sole purpose of assessing current state of PROMIS, as well as obtain RN feedback in order to develop further training and make process improvements. Because of the haste with which PROMIS was rolled out, there was no opportunity to train the RNs prior to launching PROMIS, thus the design team decided to administer this survey to the RNs three months after implementation, once RNs were briefly trained and had time to incorporate PROMIS into their workflow. We plan to administer this same survey again in January 2016, six months after implementation. Over the next three months we will take the feedback we received from the surveys and develop intervention(s) according to the identified needs of the RN, as indicated in their survey responses. We will use the January responses to compare and contrast the current survey responses

Quantitative analytic methods. The design team formulated the specific evaluation metrics, but relied completely on the EHR IT team to build the reports electronically from which the data could be extracted and reviewed. For the purposes of the initial PROMIS rollout, the primary measures of interest were (a) the total number of PROMIS questionnaires sent out (i.e. total number of patients who received the PROMIS questionnaire), (b) percentage and number of completed PROMIS questionnaires, and (c) percentage and number of *relevant answers*. The IT team also included the location where the questionnaires were filled out, whether it was completed in clinic or via their online health portal, MyHealth. SCI leadership decided upon a target completion rate of 60%. Unfortunately, no CCP has yet to meet this target.

Qualitative findings. A total of 23 RNs responded to the survey, out of 30; this represents a 77% response rate, much better than we were anticipating. While the responses provided by the 23 RNs varied, there are some overall trends.

Ease of use. The majority of RN respondents (n = 16, 56.5%) found it *somewhat easy* and *very easy* to navigate the EHR to access PROMIS (question 6 and 7).

Training and Development. While a majority of RNs indicated they received *somewhat adequate* or *very adequate* training around how to utilize PROMIS and access resources to meet patients' emotional, physical, and practical needs (question 9), only 47.8% indicated being *somewhat clear* (n = 2, 8.7%) or *very clear* (n = 9, 39.1%) in how to follow-up on identified needs (question 8).

Utility. The NC responses regarding the PROMIS questionnaire's utility is less definite, with responses dispersed along the spectrum. There is disagreement about PROMIS's effectiveness in identifying patients' emotional, physical, and practical needs. Approximately 22% of RNs report PROMIS is *somewhat effective* as a screening tool; another 22% report being *not sure*; and yet another 22% report it being *very effective* (question 1). Conversely, 43.5% report the tool as *somewhat accurately* representing patients' emotional, physical, and practical needs (question 2). There also appears to be uncertainty about the PROMIS tool's usefulness to practice. For example, 31.8% (n = 7) are *not sure* how the tool has enabled informed discussions about patients' holistic care needs and 31.8% (n = 7) indicate the tool is *somewhat helpful* in facilitating these discussions. Eighteen percent (n = 4) see the tool as *somewhat unhelpful* contrasted by 31.6% (n = 3) of RNs who see it as *very helpful* (question 3). Similarly, 31.8% (n = 7) of RNs are *not sure* if the PROMIS has helped facilitate referrals to other services; 27.3% (n = 6) think it has been *somewhat helpful*, while 18.2% consider it *somewhat unhelpful* (n = 4; see Appendix V for the detailed breakdown of responses by questions).

Quantitative findings. *Completion rates*, defined as the number of PROMIS questionnaires that were completed by patients from the total number of PROMIS questionnaires

distributed, were collected between June and September 2015. The Gynecologic and Breast Oncology clinics went live with the electronic PROMIS questionnaire in April 2015, so completion rates were collected for these clinics starting in April. During this initial month, both clinics achieved their highest completion rates: 37.3% completed in Breast and 26% completed in Gynecology. These rates quickly plummeted in the following months, with a slight increase to 17.1% completion in September for Breast and 16.9% in Gynecology (see appendix W for a detailed breakdown of completion rates by CCP).

During the initial rollout of PROMIS in the rest of the CCPs in June, the Head and Neck Oncology clinic had the greatest completion rate of 38.9%, followed by Skin Cancer and Melanoma at 24.5%, and Neurology at 16.1%. Urology showed the greatest improvement in their completion rates. Their initial rate was 3.5% in June, which increased to 14.8% in July, then 34.2% in August, and slightly dipped in September to 21.5%. To date, the highest overall completion rate is 25.3%, achieved by Head and Neck, and the lowest rate is 0% in Sarcoma followed by Lymphoma with a completion rate of 4.0%. Appendix W delineates the breakdown of completion rates per CPP by month.

Although it is not an impressive sample, we have collated six weeks of *relevant answers*. Of those who completed PROMIS, these values represent those who had one or more responses to the right of the line, meaning answers of *fair* or *poor* on one or more items on PROMIS (see Appendix I for PROMIS tool). During the first two weeks, 4.3% of patients had *relevant answers*. In week three, 5.3% had *relevant answers* and the remaining three weeks had a range of 4.8% to 3.6% (see Appendix P for the breakdown of *relevant answers*).

Section IV: Results

Program Evaluation

This evidence-based practice change project consisted of several steps with rapid PDSA cycles dispersed throughout the project planning stages and the initial three months of the project launch.

PDSA cycle number one. After the decision was made by Dr. Ramchandran and the Director of Survivorship to use the PROMIS tool, another pilot was conducted with the same MCC in the same Gynecologic Oncology physician's clinic. Patients were asked to fill out the PROMIS tool by hand at their first visit, which was then scanned into the patient's chart. However, the MCC never saw the completed PROMIS form as it was turned in with the rest of the paperwork the patient was asked to fill out prior to their visit. Therefore, positive answers went unacknowledged and as a result, untreated. Our chart review confirmed this: for patients with *positive* answers on the PROMIS tool, there was no mention of their reported symptoms in the physician visit note nor was there any follow-up documented by the MCC. This required a PDSA cycle in which the *Act* phase was to ask for the tool to be made electronic in order to improve workflow by making patient responses readily accessible, provide real-time patient responses for clinicians to see and act upon at the time of need, and track responses over time. In March 2015, this request was granted by the leadership of SCI and the PROMIS tool was made electronic.

PDSA cycle number two. With the utilization of the electronic version of PROMIS (ePROMIS) came workflow and logistical problems. The most significant of these was the destination of the completed PROMIS questionnaires. With the implementation of ePROMIS the discussed workflow was the completed ePROMIS questionnaires would be sent to the *in baskets*

or EHR related email inbox of the various providers for them to view. However, all surveys were going to all MCCs and there was no provider filter or other mechanism by which to target patients to their respective MCC- a huge oversight. Consequently, this resulted in very little action on ePROMIS responses due to the volume of questionnaires received without an owner. As soon as this problem was realized, we alerted our EHR IT support liaison to this problem. The *Act* from this problem was to stop all questionnaires from going to all in-baskets. Instead an electronic link through the EHR was created and each MCC was asked to individually assess whether or not each of their patients completed the PROMIS questionnaire.

PDSA cycle number three. With a more effectively integrated ePROMIS questionnaire, the design team began planning a pilot project in the Gynecologic Oncology clinics with all physicians, MCCs, and their respective patients. We began developing observation tools we would use for our initial needs assessment of current workflow and provider and patient engagement with the ePROMIS questionnaire. After two weeks of observation we planned to develop a standardized workflow for the MCCs around ePROMIS, making them the owner of the screening and management process. In theory this included ensuring completion of PROMIS; triaging needs in real-time; explaining the role of PROMIS as a screening tool and discussing any identified needs with the patient, in person, when they came for their physician visit; and making appropriate and timely referrals to necessary supportive services. Our plan was to begin our observation in June 2015 with plans to implement our created workflow in July, and conduct a PDSA in the beginning of August. Then, with a revised and more concrete workflow, we would then pilot in Hematology, as it would align with the role of the MCC being implemented in Hematology, and we had strong stated interest from the Hematology physicians for standard

screening and tracking. After refining the process and sharing outcomes with other teams, we then planned to develop a timeline for rollout in additional cancer care programs (CCPs).

PDSA cycle number four. Despite our plans, on June 8, 2015, SCI went live with the electronic version of PROMIS throughout all 12 of its CCPs. Not only was the PROMIS questionnaire launched electronically on this date, but the entire EHR system was changed to a specific ambulatory care interface, changing how all employees in the outpatient setting interacted with the EHR. In the two months prior, all outpatient employees went through a two-hour training on how to use the new EHR system and during this instructional session, there was mention of the PROMIS questionnaire being instituted with a brief overview on how to access it. Needless to say, on the day of rollout, it was clear no clinicians remembered how to access the questionnaire, and most did not recall that the PROMIS tool was being utilized for patient screening.

During the first two weeks of launching PROMIS, a small team rounded in all CCPs, providing electronic support and education about the purpose, importance, and intended use of PROMIS. Prior to its implementation, clinic managers met with all of the medical assistants (MAs) to review their new workflow, which now included ensuring the PROMIS questionnaire was completed prior to each patient visit. If it was not, they were instructed to assist patients to fill out the questionnaire prior to seeing their physician. Throughout these two weeks this team collaborated with the EHR IT team who was also present in the workrooms and clinics during this time. Together we provided answers to various questions, gathered feedback, and troubleshot identified problems, if possible. For the items that could not be solved straightaway, we each created our own list of outstanding issues that we took back to our respective larger teams or escalated the issues to the appropriate personnel. Two items that remain outstanding are

(a) there is no way for the patient to decline to fill out the questionnaire, and (b) the questionnaire is not currently offered in any other language other than English.

Dr. Ramchandran and the Director of Cancer Center Operations, with the consensus from our design team, decided that only return patients, prior to their second oncology visit, would receive the PROMIS questionnaire. This excluded patients who were coming in for any type of procedure or treatment; the questionnaire was only sent to patients who were seeing their oncologists for the second time. This was decided upon out of consideration for patients who often receive their cancer diagnosis along with a wealth of information at their first visit and in accordance with the guidelines set forth by QOPI.

PDSA cycle number five. After the first month of implementation, our design team along with the Manager of the Integrated Cancer Care Programs (our operational partner), conducted informal interviews with various MAs, RNs, and advance practice providers—chosen at random based on their presence and availability at the time we were circulating in the clinics—to obtain feedback on the feasibility of PROMIS and their perceived success of the tool's utilization. From these interviews it became clear that neither the MAs nor the RNs felt entirely comfortable with the tool. The MAs shared they did not feel comfortable assisting patients to fill out the questionnaire as they did not know how to answer the patient questions that arose and they did not have the time to sit with patients to complete the questionnaire. If the patient did not speak English, they had to ask for an interpreter to assist in translating the questionnaire, which took anywhere from ten to twenty-five minutes. The RNs shared that they were unsure of their role in relation to the questionnaire and also expressed feelings of unpreparedness in having potentially difficult conversations as a result of the PROMIS questionnaire.

Our *Act* as a result of this information was five-fold. First, we conducted two one-hour training sessions with a majority of the clinic MAs to review the purpose of the PROMIS tool, its content, what we were asking of them, and provided instruction on how to respond to a *positive* screening. We identified five questions if a patient answered *poor* or *very much* on any one of those questions, the MAs were to immediately inform the RN, APP, or physician depending on specific clinic workflow (see Appendix X). Second, we no longer required the MA to stay with the patient to complete the questionnaire, rather we asked the MA to set the patient up on the computer in the exam room for the patient to fill out the questionnaire while they waited for their physician.

Third, we conducted a two-hour training session with all the RNs to review with them the PROMIS questionnaire, what constituted a *positive* response, what the new MA workflow was, and also provided information and education on how to have difficult conversations. During this time we role-played and discussed various clinical scenarios. At the end of this session we formulated a tip sheet that each RN could have to help them through a difficult conversation (Appendix Y). Fourth, we determined the RNs' responsibility was to only follow-up on any questionnaire responses they were alerted to by the MA. Last, we created one-page informational documents for MAs to give to patients explaining the PROMIS questionnaire and for staff that we hung in workrooms for any member of the care team to reference (see appendices M and Z for one-page PROMIS informational pamphlet for staff and for patients, respectively).

PDSA cycle number six. In addition to the operational aspects of this project, we also collaborated with our biostatistician/evaluation specialist to design meaningful and measurable metrics for reporting and tracking purposes. After three meetings with her, we then contacted our EHR IT liaison assigned to us to ask for the reports we designed. Over the course of three

additional meetings we solidified our specified reports. This component, arguably the most important, was the most difficult deliverable to obtain. It took over two months to receive our initial requested reports, delaying any further PDSA cycles.

PDSA cycle number seven. This next cycle will take place after the submission of this paper. In this next cycle we will analyze the data and refine our current processes going forward. We will use the data to respond to the following questions:

- Should we change what we are considering to be a *positive* screen from one item to two?
- Should we open up screening to more than just those coming for their second oncology visit to include patients coming for procedures and treatment?
- If we find a significant increase in referrals, do we need to formulate a business plan asking to increase our supportive care services workforce to accommodate the increase in patient volume?
- How can we best evaluate impact on screening and supportive services on patient outcomes?

Our next steps include ongoing PDSA cycles to identify successes and failures of first phase and develop second phase with the goal to achieve ideal state within 6 months. We also intend to refine the algorithm for referral to PM/support services and revise the referral process to PM/support services based on ongoing analysis of patient characteristics and self-reported needs. We also hope to build the algorithm into electronic referral prompts based on *relevant answers*, any responses of *fair* or *poor* on any of the items. In addition to this sophisticated use of the EHR, we hope to also develop electronic triggers that indicate *relevant answers*. Lastly, we hope

to acquire and use iPads for survey completion in the waiting room prior to a patient's clinic visit.

Outcomes

Since launching the PROMIS questionnaire in June 2015, both our qualitative and quantitative findings were used for program improvement. We continue to analyze the data, assess current processes, and develop strategies that will continue to promote integration of screening, assessment, and management of comprehensive care needs into cancer care. We still need to develop more concrete workflows for both MAs and RNs as well as design clinical care pathways so that RNs know how to respond to identified needs. Some of our next steps to address the current gaps and respond to the feedback we received from the RNs through our survey include the following: incorporate the use of a standard electronic *smartphrase* for PROMIS which the nurse could use to document discussions around PROMIS, develop a PROMIS-specific referral, and create standard work around reviewing PROMIS. Many RNs do not see patients in clinic. Building in the process around nurse navigation and advocacy in addressing survey responses is needed as well as figuring out how best to communicate survey responses to physicians.

In response to the concerns voiced by many of the MAs and from our observations of current practice around PROMIS screening, additional next steps will focus on increasing online completion of PROMIS as well as completion of the questionnaire outside of clinics. This goal is to take the responsibility for questionnaire completion out of the hands of the MAs. We also hope that the creation and implementation of best practice alerts will decrease the workload of the MAs as they will no longer be responsible for alerting the RN or MD to *relevant answers* as these best practice alerts will populate upon questionnaire completion for the RNs, APPs, and

MDs to easily see. Until these electronic support pieces are being developed and tested, we plan to institute a reward system for the MAs, which will recognize and celebrate certain MAs and CCPs who obtain the target questionnaire completion rate of 60%.

Although we are waiting on the total number of referrals to social work and palliative medicine in order to compare these numbers to the number of referrals to these services prior to the implementation of PROMIS, from informal conversations with both social work and palliative medicine, there seems to be an increase in the number of referrals to both of these services as a result of PROMIS. There is also a shared notion that many of the indicated *positive* responses are addressed in the first call or first visit with either team. While this is not true qualitative data, this observation is useful, and demonstrates a seemingly more effective closed loop communication system.

Section V: Discussion

Summary

Key successes. The ability to implement this project on such a large scale is one of the greatest successes of this project. The expediency by which this project was executed affords good and bad consequences, however. It is common at a large academic center for the implementation of practice changes to be drawn out as there are several layers of approval needed. Although its conception began two years ago, once the PROMIS tool was decided upon as the assessment tool, its incorporation into practice did not seem to encounter any barriers. While there was resistance and hesitancy, mostly by the MAs and RNs, the leadership of SCI whole-heartedly endorsed this project by considering it a priority for the organization.

Additionally, the use of an electronic screening tool allows for many sophisticated, evaluation metrics and reporting functionality as well as allows for greater efficiencies both in

patient completion and clinician review. These capabilities will provide real-time information to patients and clinicians as well as allow clinicians to track responses (i.e. symptoms) overtime. Additionally, having an electronic screening tool embedded into the EHR system enables the development of electronic algorithms which can serve as clinical care pathways, automate referrals, and develop clinical decision support tools such as best practice alerts to enhance efficiency and help ensure needs do not go unidentified.

Lessons learned. First, while a major component of this project focused on the screening tool itself—its selection, feasibility, and electronic format capabilities—a significant learning point is that it is not about the instrument itself, but the process of identifying needs by way of the instrument to adequately assess and manage identified needs. In other words, the actual screening tool does not determine the outcome(s), rather the goal is to use the instrument to identify needs so they can be met.

Second, any large-scale intervention requires effective frontline clinicians to ensure the desired outcome(s) are accomplished. We found that in-person support in real-time was greatly beneficial for the MAs and RNs specifically, as they primarily interacted with patients around the PROMIS tool. Additionally, because operational barriers are critical issues to overcome when implementing distress screening, ongoing training and engagement is critical.

Third, it takes more than having a good idea to make a change successful; it takes operationalization. Therefore, having an operations process owner (the Integrative Cancer Care Program (ICCP) Service Center Operations Manager) is helpful for implementation, accountability, and sustainability. Fourth, the incorporation of PROMIS into clinical workflow needs to be intuitive and easily accessible. Criticism already existed around the amount of time spent in front of a computer and how navigating the EHR can detract from face time with

patients (Block et al., 2013; Friedberg et al., 2013). This further corroborates our efforts to encourage the completion of PROMIS questionnaires online or while waiting. This will allow clinicians time to review questionnaires prior to patient visits so that responses can be discussed in person during the visit.

Next steps. There is still much work to be done to maximize the capabilities of electronic PROs through PROMIS. We still desire to gather more information on how PROMIS is changing practice and impacting patients, as well as clinicians, hopefully for the better. In order to evaluate whether screening is indeed increasing patient access to supportive services (i.e. palliative care or social work), we would like a specific PROMIS referral so we can easily capture this. From the findings, we could potentially make a case for more staff to provide these services. Furthermore, we would like to be able to know if providers truly are following up on *relevant answers*. In order to do this we have asked for IT to create a *smartphrase* which would be incorporated into a clinicians electronic visit note that would populate a dropdown menu from which the clinician could indicate the action that was taken in response to the *relevant answers* identified (e.g., responses discussed and addressed during visit, no further action required, medications prescribed, or referral made). Additionally, we would like this note to be a hard stop in the medical record for all patients with *relevant answers*, meaning the provider would not be able to close the patient encounter until this action step was completed.

An additional step toward sustainability would be staging. Currently, SHC as an organization does not stage cancers (e.g. stage I, II, III, IV). While requiring every oncologist to stage cancer would be difficult, doing so would allow the opportunity to perform more sophisticated electronic data collection, analysis and stratification of patient needs. For example, it could potentially allow us to correlate cancer stage and/or type of cancer with specific resource

need(s) and utilization. Another step toward sustainability that is currently underway is to establish more robust electronic decision-making support capabilities. This includes building an algorithm that would generate automatic referrals to supportive care services. The purpose of this is to prompt clinicians to either choose to send the referral or choose to address the patient needs within their own team. We also hope to develop electronic triggers to indicate *relevant answers* for more efficient and effective identification of unmet needs.

Next, we plan to be transparent with our findings and engage in sharing our information with patients and clinicians to further foster engagement and teamwork. We plan to send out monthly reports to all SCI clinicians on PROMIS utilization, very similar to our process measures, which include the number of questionnaires distributed, the number of questionnaires completed, the percentage with *relevant answers*, and the number of referrals generated as a result. Lastly, we need to develop strategies to measure whether patients feel their needs are actually being met by way of screening. One way we plan to do this is to analyze our Press Ganey scores along with additional survey questions to distinguish whether there have been any positive impact, as measured by patients' survey responses. Our team believes in practicing ongoing PDSA cycles to identify successes and failures of each phase and develop subsequent phases to achieve ideal state. Eventually, we hope to have the reporting structure in place to make comparisons among the number of referrals to supportive services pre-PROMIS compared to after PROMIS, as well as identify if the number of emergency room visits and inpatient hospitalizations pre-PROMIS differ from post-PROMIS implementation. Ideally, we hope to see an increase in supportive services utilization and a decrease in the number of emergency room visits and inpatient hospitalizations due to earlier identification and better management of patient needs and symptoms.

Relation to Other Evidence

There has been much work in recent years to devise standards of psychosocial care, develop clinical practice guidelines, and formulate measurable indicators to assess the quality of psychosocial care provided in oncology practice settings (Jacobsen & Wagner, 2012). Distress is not a stranger to cancer patients. In fact, given its broad definition, distress quite possibly may touch the lives of all cancer patients and those close to them at some point along their cancer care trajectory. Because of its pervasiveness, national and international interventions have been put into effect to have distress recognized as the sixth vital sign to heighten awareness and bring focus to the importance of assessing and managing patient concerns (Dudgeon et al., 2012; Watson &, 2010; Bultz & Groff, 2009; Bultz, Thomas, Stewart, & Carlson, 2005).

Between 2005 and 2012, there has only been a 7% increase in the use of screening tools for routine assessment by NCCN Member Institutions. There is additional evidence that suggests that without the use of screening, cancer care providers do not adequately assess for symptoms or identify distress (Lazenby, 2014; Chen, Ou, & Hollis, 2013; Jacobson & Wagner, 2012; Bultz & Groff, 2009; McNiff, Bonelli, & Jacobson, 2009). The *NCCN Clinical Practice Guidelines in Oncology for Distress Management* were first developed in 1999. These guidelines are nationally recognized as the gold standard for the provision of high quality patient-centered cancer care (Lazenby, 2014; Jacobsen & Wagner, 2012). Per these guidelines, distress is defined as

> a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends a long a continuum, ranging from common normal feelings of vulnerability, sadness, and

> fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. 7)

These guidelines provide clear instructions on when and how to best practice distress management. A few of the recommendations include the following:

- distress should be identified, evaluated, documented, and readily treated at all stages of disease;
- all patients should be screened for distress at their initial visit, at appropriate intervals and as clinically indicated (i.e. changes in disease status or treatment-related complications);
- clinical health outcomes, quality of life and patient/family satisfaction, should be measured when evaluating distress;
- management of distress is an integral component of the provision of care and information about psychosocial support services should be provided to all patients and families; and
- institutional quality improvement projects should include evaluating the quality of distress management.

The primary reason to screen for distress is to identify patients who may be in a situational period of increased vulnerability or at an increased risk for distress. These characteristics are clearly detailed in the guidelines. These guidelines provide various algorithms for patients who are experiencing varying levels of distress. The NCCN guidelines utilize the Distress Thermometer and Problem Checklist as their initial screening tools and have determined a score of ≥ 4 on any of the items on the Distress Thermometer to indicate moderate to severe distress. The algorithm suggests that any patient in "mild distress" should be first triaged by their primary oncology team and if necessary, receive a referral for psychosocial support. If patients are identified as high risk; have practice, family, physical, social, or emotional problems; or have

spiritual or religious concerns, they should receive a referral to mental health services, social work, counseling services, or chaplaincy services, whatever is deemed appropriate by the referring clinician. Follow-up, communication, and collaboration with primary oncology team as well as with family and caregivers is also recommended (NCCN, n.d.).

The IOM report (2008), *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, was a pivotal manuscript that brought psychosocial care to the forefront of cancer care clinical practice. The report underscored the deficiencies in how we care for the wellbeing of the cancer patients we so aggressively, innovatively, and scientifically treat with medical interventions, often disregarding their potential psychological or social problems. In 2011, the American College of Surgeons (ACoS) founded the Commission on Cancer, a program dedicated to creating the framework through standard setting, prevention, research, education, and monitoring of comprehensive quality care so cancer patients may experience improved quality of life and greater longevity. With the focus on quality of care and health outcomes, the Commission on Cancer created *Cancer Program Standards: Ensuring Patient-Centered Care* which includes standards for distress screening with psychosocial intervention and management of identified distress (American College of Surgeons (ACoS), 2012).

The American Society of Clinical Oncology (ASCO) through their Quality Oncology Practice Initiative (QOPI) program has recently required routine psychosocial assessment and management of cancer patients as part of their accreditation standards. More specifically, all patients must be screened for distress by their second oncology visit. This initiative has called on the oncology community to screen for distress among cancer patients (ASCO, n.d.; McNiff, Bonelli, & Jacobson, 2009). This benchmark, along with the guidelines for standards of psychosocial care developed by the NCCN, ACoS, and the IOM, are endorsed by the American

Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS), who are also making efforts to implement these practice standards on a national level (Pirl et al., 2014).

Distress management through PRO has gained popularity in recent years as it has proven to be an effective way to screen for a variety of health care needs. PRO questionnaires provide an avenue for patients to self-report a multitude of symptoms, physical functioning, mental health, and quality of life. This insight creates the platform upon which clinical practice can be enhanced. The use of ePRO systems allows for better symptom monitoring, improved communication among a variety of providers, increased efficiency, and the capability to monitor patient symptoms over time. Collecting patient responses electronically also allows for real-time alerts to clinicians if severe symptoms are present, which is potentially time-saving.

PRO questionnaires were first implemented in the setting of clinical trials to assess product effectiveness (Bennett, Jensen, & Basch, 2012). Since then, several institutions have incorporated ePRO systems into routine oncology practice. Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University, Duke Comprehensive Cancer Center, Memorial Sloan Kettering, MD Anderson Cancer Center, Dana Farber Cancer Institute, Cancer Care Ontario, and the West Clinic in Memphis, Tennessee represent the majority of organizations practicing screening for distress and comprehensive cancer-specific needs (Bennett et al., 2012; Basch & Abernethy, 2011). This evidence-based quality improvement project now places SHC among these world leaders in screening.

Cancer Care Ontario (CCO) is a pioneer in implementing routine screening for emotional distress. In 2006, Dudgeon and her colleagues launched a province-wide initiative to screen cancer patients for emotional distress using the Edmonton Symptoms Assessment System

(ESAS). This project, named the Provincial Palliative Care Integration Project (PPCIP), was an initiative endorsed by the cancer centers as well as the community and funded by a variety of sources to improve care for cancer patients. It was initially piloted with lung cancer patients only. In addition to screening, algorithms were developed to ensure adequate follow-up on any identified physical or psychosocial need. This team also developed a system known as the Interactive Symptom Assessment and Collection (ISAAC) to collect ESAS responses via touch-screen kiosks at the clinic or via the internet. The system maintains a database of each patient's demographic information as well as their responses to the ESAS questionnaire. In 2008, the PPCIP became the Ontario Cancer Symptom Management Collaboration (OCSMC) and screening was expanded to all cancer patients throughout all 14 Regional Cancer Centers (Dudgeon et al., 2012).

In the first year of the pilot study, screening with ESAS increased from 3.5% to 47 %. By the end of the first year, over 10,000 ESAS's were completed per month. Eighty five percent of patient respondents indicated that ESAS was an important component of their care as it helped providers know how they were feeling; 62% reported good control of their pain and other physical symptoms, and 61% reported feeling their providers incorporated their ESAS responses into their plan of care (n = 407). Two years later, in 2009 after screening was launched for all cancer patients, 89% of patients felt the ESAS was important to complete, 79% reported their providers incorporated their ESAS responses into their plan of care, and 78% reported their symptoms were well controlled (n = 844). These responses indicate that improved symptom screening with subsequent documentation leads to improved patient care. While their goals of screening 90% of all lung cancer patients and 60% of the rest of the cancer population have yet

to be achieved, Dudgeon and her colleagues remain hard at work to improve the cancer patient experience across the continuum of care through symptom screening (Dudgeon et al., 2012).

Like CCO, Northwestern is another leading organization in the implementation and utilization of electronic administration and scoring of PROs for symptom assessment. PROs has become the new gold standard for quantifying patient subjective complaints—physical, emotional, spiritual, and psychosocial—and have been found to provide meaningful information to patients and clinicians alike. The integration of PRO tools into electronic systems have proven to be feasible, efficient, and provide helpful insight into patient experiences (Wagner et al., 2015; Bennett et al., 2012).

Wagner and colleagues (2015) implemented the computer adaptable PROMIS screen, which was integrated into their EHR system, to assess cancer-related symptoms and real-time communication of how PROs influence clinical practice. Six hundred thirty six gynecologic oncology patients at the Robert H. Lurie Comprehensive Cancer Center in Chicago, Illinois, comprised the study population from November 2011 through February 2014. The PROMIS computer adaptable test (CAT) was administered to assess pain interference, fatigue, physical function, depression, and anxiety. An additional psychosocial assessment tool was created from the NCCN Distress Thermometer and Problem Checklist and a nutritional assessment was adapted from the Patient-Generated Subjective Global Assessment. There were a total of 40 questions taking, on average, ten minutes to complete (Wagner et al., 2015).

Only patients with a *MyChart* patient portal account could participate. Every two hours prior to their clinic visit they received a message prompting them to fill out the PRO assessment with instructions on how to do so. If patients did not complete the assessment prior to their visit they were given an iPad upon check-in to complete the assessment survey while waiting.

Assessment results were documented in a specific section in the EHR in real-time. Clinicians could easily pull these results into their notes and messages were sent to their EHR inbox if the patient reported severe symptomatology (Wagner et al., 2015).

Clinical messaging algorithms were developed for each domain assessed. Patients were asked for their preferred mechanism for follow-up: *MyChart* emessage or a telephone call. Eighty four percent of patients indicated they preferred to be contacted through a *MyChart* emessage. The electronic PRO (ePRO) assessment was linked with clinic visits: 301 patients completed the assessment twice, 184 answered it three times, and 129 patients completed the assessment four times. A total of 4,404 assessment requests were sent through *MyChart* across the two-and-a-half-year project timeline. From this total, 3,203 messages were viewed, 1,493 assessments were started, and 1,386 assessments were completed signifying a 93% completion rate. The authors also measured the completion rates of first assessment requests only: a total of 1,089 first assessment requests were sent. Of these, 435 were started (40%), but only 401 were completed, representing a 37% completion rate, a somewhat disappointing overall return rate (Wagner et al., 2015).

Impairment in physical functioning was the most common PRO. *Severe* was classified as a T score of greater than or equal to 70. Forty percent of patients (n = 26) had symptom scores in the severe range for physical functioning. Fifty one percent reported pain interference as mild or greater; 47% reported fatigue above normal; 43% reported anxiety as mild or greater. Only one patient reported severe anxiety or depression of the 67 patients who completed the psychosocial assessment; 66% (n = 407) reported no psychosocial concerns. Of the concerns reported, information on advanced directives, support with managing stress, and information on financial resources were the top three areas of need. From the 541 patients who completed the nutrition

assessment, 33% generated an electronic notification to the dietician. A majority of the messages were inquiries requesting information on gaining or losing weight, feeling full quickly, loss of appetite, nausea, constipation, and taste change management.

Northwestern University is one example of a program that has successfully integrated a robust psychometrically ePRO assessment into daily clinical practice. This enhanced clinician workflow as screening provides insight into patient concerns and allows for more focused clinic visits and symptom tracking over time. Efforts are underway to evaluate outcomes of PROs screening (Wagner et al., 2015).

Duke University has also successfully implemented an ePRO system into their oncology clinics for the purpose of identifying distressed patients and providing optimal cancer care. After conducting a validation study among patients with breast, lung, and GI cancers to confirm its psychometric properties, Smith, Rowe, and Abernethy (2014) chose the Patient Care Monitor (PCM) version 2.0 as their data collection system. This system is made up of software, ePRO review of system assessment survey, analytics and reporting infrastructure, and integration into care. The authors used etablets as the mode of survey administration and collection. Neither the timing nor the frequency of survey administration was detailed, but reports were generated at each visit highlighting areas of concern and, if applicable, would generate a past history trending report. A score of 65 or greater on the Distress and Despair subscale or the selection that they would be “better off dead” indicated a need for a referral for psychosocial services. A nurse generated this referral (Smith et al., 2014).

Approximately 11% met referral criteria (n = 17, 338 patient encounters; Smith et al., 2014). With the implementation of ePRO, the authors have observed greater access to PC services and increased collaboration and communication among the primary oncology teams and

the psychosocial providers. Like Wagner et al. (2015), they also found ePRO implementation to improve clinic workflow as well as experienced a cost savings as manual data entry was no longer required (Smith et al., 2014).

Given the amount of attention distress screening has received by well-respected national and international organizations and the initial quality improvement projects piloted by various leading institutions in cancer care, the work of this evidence-based practice change project is establishing SHC among these top leaders. Given the work that has gone before and in accordance with the psychosocial care guidelines and standards of care that have been developed in response to the overwhelming need to take better care of cancer patients' wellbeing, SHC is actually better positioned than many of its predecessors. This project focuses on identifying cancer patients' comprehensive care needs through ePRO screening and addressing these needs through algorithmic clinical care pathways, as well as developing metrics to measure health outcomes, an important missing component to distress screening highlighted throughout much of the literature.

Barriers to Implementation

The extent of the barriers encountered during this evidence-based practice change project stemmed from a general misunderstanding or under appreciation for the work and expertise of palliative medicine by both clinicians as well as patients. It is possible that the same could be true of social work, at least at an organizational level; however, this author is not well versed in the literature to generalize this statement to the greater healthcare system. In retrospect, more time to explain the nature of the project to frontline staff so as to get their buy-in would have improved implementation. Additionally, this would have allowed for the development of a more thoughtful implementation strategy and evaluation plan. While the decision to launch PROMIS

provides many benefits and opportunities, as well as allows SHC to be among the leading institutions which are screening for psychosocial distress early in a patient's cancer diagnosis, the short timeframe within which this was executed brought a handful barriers and limitations as a result.

One of the biggest frustrations and subsequently a primary limitation of this project was the lack of a formal IT infrastructure in place prior to implementing PROMIS. One of the main requests of the physicians and advanced practice providers (APPs) in the beginning development stages of this project was the capability to obtain data from their patients' PRO and to track responses over time. Currently, both of these reporting configurations remain undeveloped. Therefore, during the initial months of the rollout the team received many questions about the tool's utility, feasibility, and patient characteristic information and correlation to various support services accessed for which answers were unavailable.

With the launch of PROMIS, our team was assigned an EHR IT support technician, which was very helpful; however, the expertise of this person was limited to only certain IT functionalities so when our request went outside of our contact's expertise, we then had to meet with other personnel, taking several weeks in some cases to get in touch with the appropriate person. In addition, once contact was made and conversations were had, it was also several weeks before we received any reports. Per our IT contacts, this delay was due to the fact that the new ambulatory EHR build was rolled out at the same time as PROMIS, and they only had so many resources and allotted time to devote to our requests, another confounding limitation of this project.

Another significant limitation of this project was that there was little time to adequately plan the implementation of this project. Our team was told two weeks prior to the *go-live* date

that PROMIS was going to be implemented electronically SCI-wide, which meant we had to set aside our plans for a pilot project, and scramble to figure out how best to support staff and patients during this time. The lack of standardized processes and ownership of the PROMIS tool was a significant limitation. This, in turn, resulted in the absence of formal training of MAs, RNs, and APPs around the tools purpose, functionality, and processes. Furthermore, this lead to a lack of clarity in role responsibility and workflow, which are central building blocks for successful and sustainable implementation.

Also as a result of the hurried implementation timeline, no scoring system was developed. The PROMIS tool does not have a formal scoring guide; therefore, our team decided that any patient with at least one response of *fair* or *poor* or *very much* is a positive screening (termed *relevant answers*) and action should be taken. Although we were in the final stages of developing a triage algorithm for RNs and APPs to follow based on patient responses on PROMIS, this process was halted as a result of the PROMIS rollout. Thus, we instructed RNs and APPs to only respond to the patients who had *relevant answers* based upon their already existing assessment and referral processes. It is quite possible that this arbitrary score caused us to overestimate patients who qualify for a referral to social work or palliative medicine.

Two additional significant barriers to this project were lack of clinician buy-in and time constraints on the part of both the MAs and RNs. As mentioned previously, there was almost universal acknowledgment of the need for standardized screening and clinical care pathways for addressing identified needs; but once actualized, the support for this endeavor was largely absent. As a whole, the MAs did not think it should be their responsibility to ensure completion of the questionnaire nor did they have the time to do it, and the RNs did not want to be responsible for following up on the questionnaire responses given their full workload, although

these are all responsibilities consistent with their respective scopes of practice. Physicians and APPs were largely excluded from the initial rollout phase, outside of being educated on what PROMIS is and where to access the questionnaire in the EHR, and future plans have not been solidified as to the extent of their role and involvement moving forward.

Interpretation

Qualitative. While our mixed methods analysis did not produce the successful results everyone hoped for in implementing a new practice change, our qualitative findings were more favorable than our quantitative. From the RN responses we received, there appears to be overall buy-in in the purpose and value of PROMIS, but gaps in knowledge around process and understanding of their role in screening and utilization of PROMIS were further highlighted by the survey. This is not a surprise as our team was also aware of these deficits, which were a result from the inability to solidify a standard workflow prior to implementation. This was also evident from our informal conversations with RNs during our clinic walkthroughs during the first two weeks of launching PROMIS. Beyond initial teaching, the capacity of our team members to return to clinics to monitor whether PROMIS was actually being implemented was nonexistent, leaving no accountability for utilization and implementation of PROMIS into standard everyday practice, which mostly likely played a role in the poor integration of PROMIS into daily workflow. We have plans to solidify a standard RN workflow and clinical care pathway in our next phase of PDSA. Additionally, we plan to administer the already developed MA survey for their feedback.

Quantitative. There is much room for improvement to achieve a 60% completion rate throughout SCI. However, there are several factors that could have influenced the results we obtained. First, the total number of return patient visits, which is the denominator of our

statistical equation, was most likely falsely inflated. This is because this number includes patients coming for chemotherapy or radiation treatment visits, which were not given PROMIS questionnaires. Only those patients who were seeing their oncologist for the second time received a PROMIS questionnaire.

Currently, there is no option for patients to decline taking the questionnaire. This means questionnaires remain unanswered, not only potentially reducing patient satisfaction, but also artificially inflating the denominator. If patients could opt to decline the questionnaire, they should be evaluated as a separate category for statistical purposes; for example, out of X number of patients who received a questionnaire, Y percent declined to answer. An additional contributing factor to the poor completion rate was the fact that not all CCPs have implemented PROMIS; not all CCPs have formally adopted this process nor have they promoted its implementation and incorporation into practice. This factor also contributes to a larger denominator of return patient visits that have not completed the survey because it has not been encouraged by their oncology team, despite receiving a *MyHealth* reminder.

Candidly, our team was somewhat surprised by the low percent of patients with *relevant answers*. There are a couple reasons for this. The first reason could be from human data entry error as all of the relevant answer data were entirely collected by one individual, who manually reviewed patient charts looking for patients with *relevant answers*, leaving room for exclusion of some patients with relevant answers or other data entry errors. Every week there were CCPs with zero *relevant answers* but there was no way of knowing whether this was because patients truly did not have any issues to report, whether patients did not fill out the questionnaire, or whether CCPs were overlooked during manual chart review.

Second, we currently have no process in place and no standardized electronic documentation indicating if *relevant answers* have been addressed. This could potentially lead to duplication of relevant answer identification. Our team is in the process of working with IT to create a hard stop in the EHR that will force the provider to select an action that was taken in response to the relevant answer(s), such as need(s) addressed during visit or referral placed. This will in turn reset the questionnaire for the next time it is to be completed and remove the relevant answer electronic alert.

The one advantage of having a small number of patients screening *positive* with *relevant answers* is that we will have the bandwidth to provide services to these patients. However, it is difficult to make inferences or conclusions from this small sample of patients with *relevant answers* so we will continue to manually collect information until our IT team can provide this information, electronically, for us. Our hope is to eventually identify specific patient populations with *relevant answers* so we can better meet their needs and even anticipate them. Because we currently do not have a system in place to identify patient characteristics, demographics, cancer type or stage of disease, it is hard to identify if there is a disease group and/or patient population that is more prone, or likely, to have *relevant answers*.

Conclusions

Cancer does not discriminate. It invades the lives of people of all demographics, each socioeconomic class, every race, the spectrum of ages, male and female alike. No matter the relationship, cancer leaves a mark on the lives of everyone it touches. Therefore, it is essential to attend to the holistic needs of patients, families, and caregivers. Early identification of palliative care needs and integration of palliative services into routine oncology care is essential to adequately meet the complex care needs of patients with cancer (Quill & Abernethy, 2013;

Smith et al., 2012). Palliative care is an emerging specialty committed to managing the physical, psychosocial, emotional, and spiritual needs of oncology patients, their family members, and caregivers. When utilized early in the cancer diagnosis, the influence of palliative care improves quality of life based on patient-decided goals, enhanced coordination of care, decreased occurrence of unwanted and unnecessary medical interventions, increased life expectancy, and decreased costs (National Quality Forum, 2012).

However, while there has been an abundance of literature on the benefits of palliative care with oncology care early in the diagnosis of cancer, how early to intervene remains unknown. Whether palliative care should be offered to patients with curable disease or without symptoms is still a topic of much debate, highlighting the fact that there is still no agreement on the criteria for specialist palliative care. Additionally, there remains variability in the extent to which palliative care is provided by primary oncologists given the range of skills, comfort levels, and palliative care services offered. Furthermore, when and where palliative care should be provided has yet to be determined (Hui & Bruera, 2013).

What we learned from this project is the utilization of a screening tool is only the method by which assessment and evaluation of comprehensive care needs is initiated. Evidence-based practice guidelines and clinical care pathways must also be in place to manage each symptom identified in a standardized way. Standard screening using PRO and clinical care pathways may foster early identification and management of patient's psychosocial and physical needs. Support for oncology nurses to lead assessment and connect patients with resources is an opportunity to incorporate primary palliative care into oncology practice. The use of structured, adaptive, novel algorithms is a promising approach to meet patient needs and improve access to supportive

resources. Oncology nurses are ideally situated to provide quality, accessible interdisciplinary care coordination crucial to patient-centric management of cancer care across the continuum.

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Appendix A: Letter of Approval

STANFORD UNIVERSITY SCHOOL OF MEDICINE

Kavitha Ramchandran M.D.
Clinical Assistant Professor
Medical School Office Building, Rm 279
1265 Welch Road
Stanford, CA 94305-5475
Telephone: (650) 723-6750
Fax: (650) 723-8596

November 6, 2015

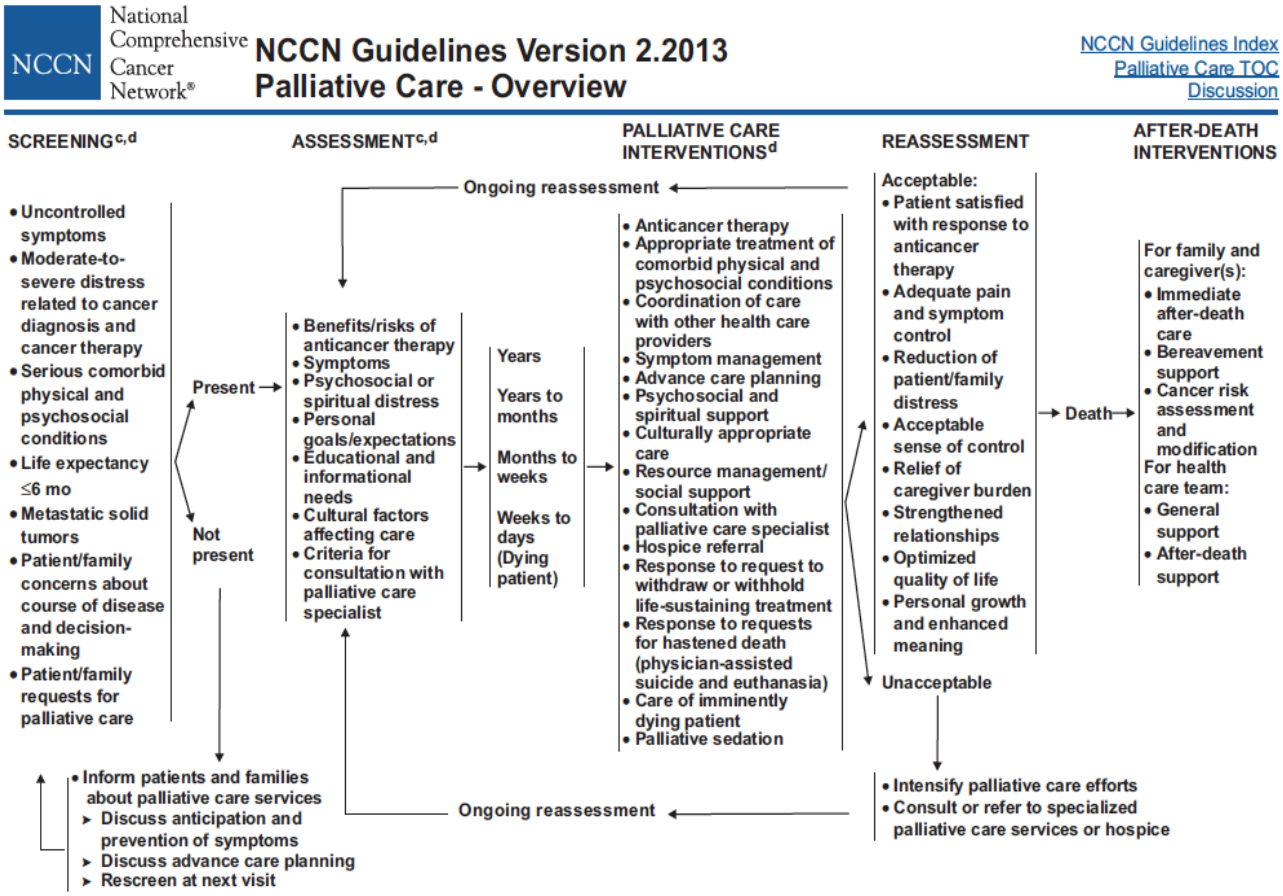
To the University of San Francisco School of Nursing and Health Professions DNP faculty,

This letter grants approval for Alison Morris to implement her DNP Comprehensive Project at Stanford Health Care/Stanford Cancer Institute. We give her permission to use the name of our agency in their DNP Comprehensive Project Paper and in future presentations and publications.

Sincerely,

Kavitha Ramchandran, MD

Appendix B: NCCN Palliative Care Screening Guidelines



National Comprehensive Cancer Network®

NCCN Guidelines Version 2.2013
Palliative Care

NCCN Guidelines Index
Palliative Care TOC
Discussion

SCREENING[c,d]

- Uncontrolled symptoms
  or
- Moderate-to-severe distress related to cancer diagnosis and/or cancer therapy
  or
- Serious comorbid physical, psychiatric, and psychosocial conditions
  or
- Life expectancy ≤6 mo
  - Indicators include:
    - Metastatic solid tumors
    - Many stage IV cancers
    - Poor performance status
      ECOG ≥3 or KPS ≤50
    - Hypercalcemia
    - Brain or cerebrospinal fluid metastasis
    - Delirium
    - Superior vena cava syndrome
    - Spinal cord compression
    - Cachexia
    - Malignant effusions

  or
- Patient/family concerns about course of disease and decision-making
  or
- Patient/family requests for palliative care

ASSESSMENT BY ONCOLOGY TEAM

Present

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial distress

→ See PAL-4

- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care

→ See PAL-5

- Criteria for consultation with a palliative care specialist

→ See PAL-6 and PAL-7

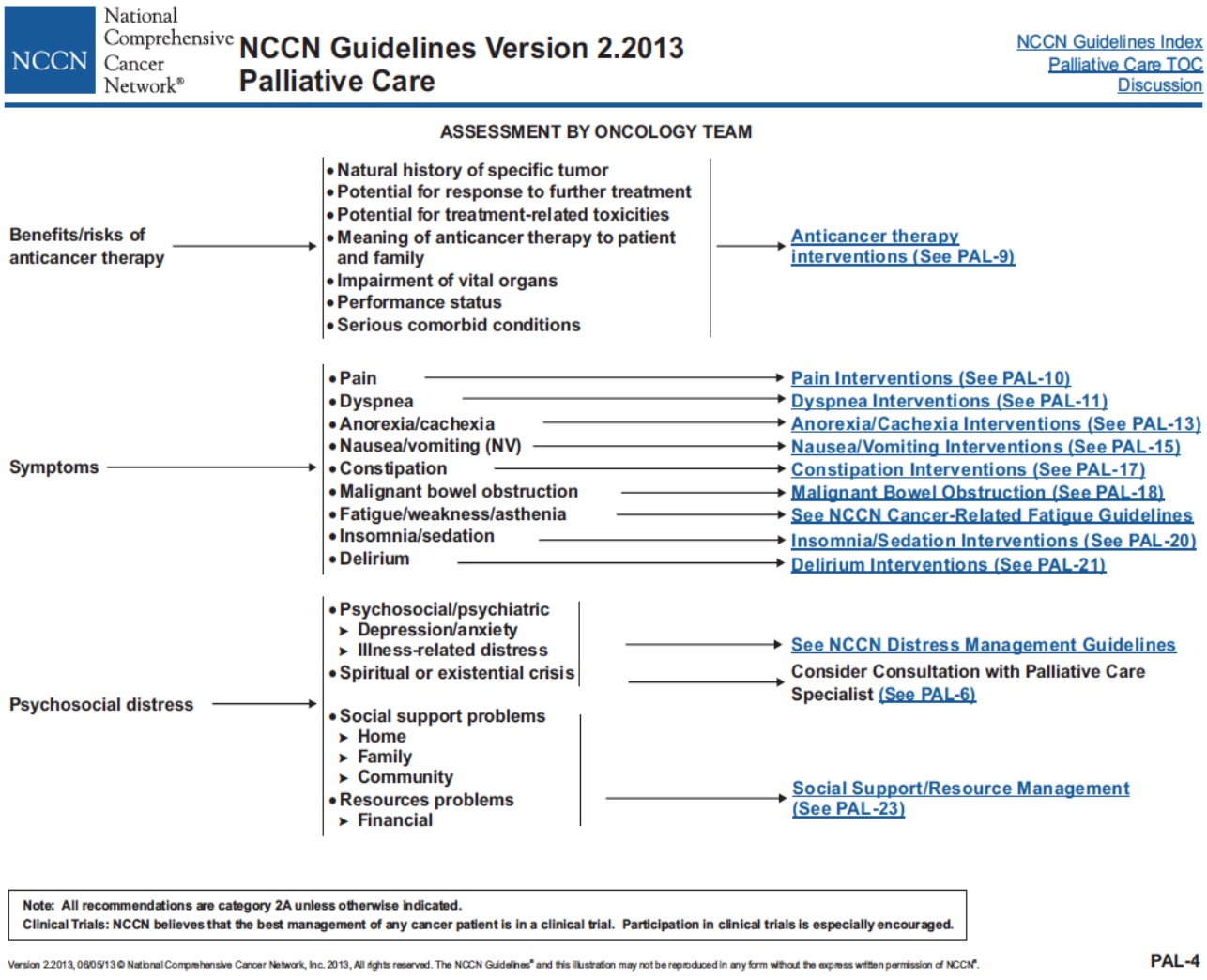
Not present

- Inform the patient and family about palliative care services
  - Discuss anticipation and prevention of symptoms
  - Discuss advance care planning
  - Rescreen at next visit

[c]Management of any patient with positive screening requires a care plan developed by an interdisciplinary team of physicians, nurses, social workers, and other mental health professionals, chaplains, nurse practitioners, physician assistants, and dietitians.

[d]Oncologists should integrate palliative care into general oncology care. Early consultation/collaboration with a palliative care specialist/hospice team should be considered to improve quality of life and survival.

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.



Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

Appendix C: Results from Chart Review

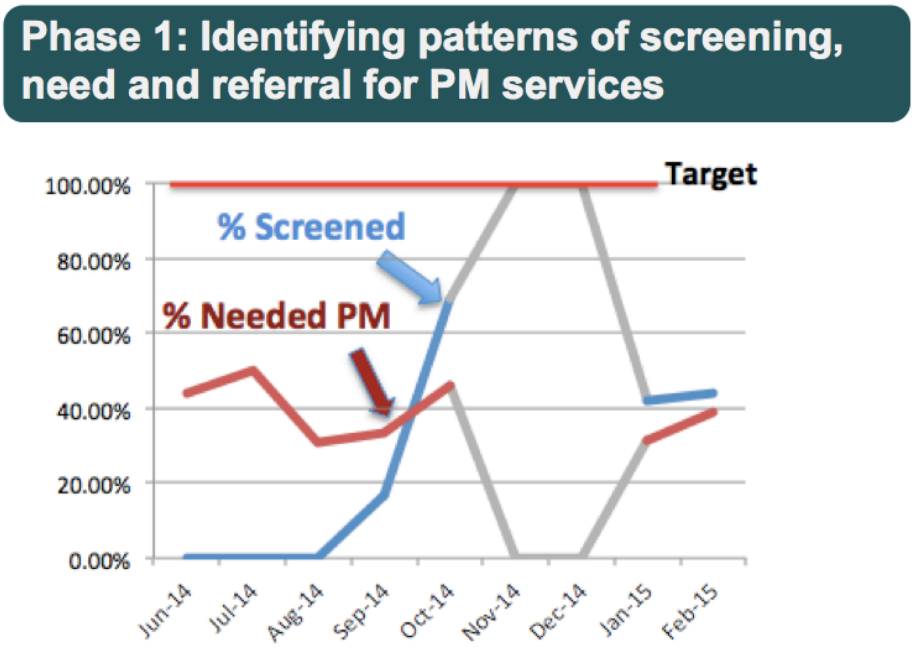


Figure 1. Percent of patients screened and percent of patients meeting NCCN criteria for PM need

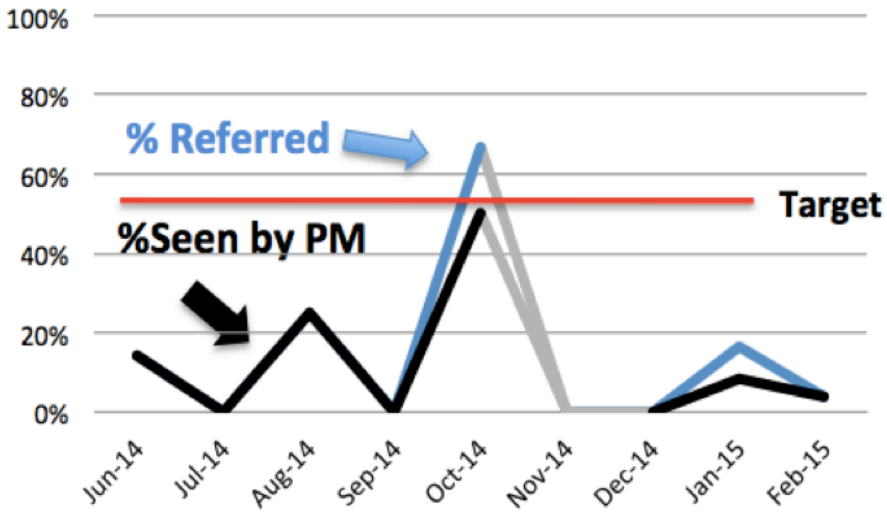
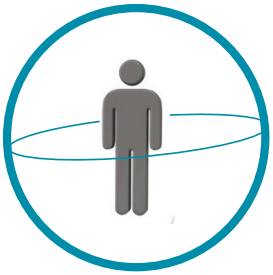


Figure 2. Percent of patients referred to and seen by a specialist palliative medicine team

Appendix D: Gap Analysis Inspired by the Chronic Care Model

Element	Gaps Identified	Gaps Met	Proposed Solution
Delivery System Design Efficient and effective provision of care	• Poor involvement of interdisciplinary care teams • Fragmented care • Lack of orchestrated palliative care (PC) clinical pathways	• Establishment of both inpatient and outpatient PC teams, consisting of physicians, APPs, CNSs, and SWs • Organization supportive of Palliative Medicine	• Integration of PC teams into routine oncology care through the co-management of cancer diagnosis
Decision Support Utilization and Implementation of evidence-based practice	• Lack of knowledge of palliative medicine/Patients unaware of what it is • Name "palliative care" has negative connotation; associated with death • Referrals based on individual physician/APP choice/preference	• PC teams actively see patients • Brochures created and patients who receive consults are educated on PC	• Development of a clinical care pathway for PC that will allow for patients to decide if needed/wanted.
Self-Management Support Patient empowerment	• Delayed recognition or inquiry of patients' preferences, desires, or goals • Lack of knowledge re available resources/support • Poor access to care • Lack of advance care planning	• Well established free Cancer Supportive Care Program offered at Stanford Health Care	• Coordinate PC appointments with other appointments so that patients may benefit from services • Involve PC early or encourage providers to ask about patient preferences and goals at the time of diagnosis • Provide advanced care planning early on in disease trajectory
Clinical Information Systems Using Information Systems to proactively inform patient care	• Difficult to identify patients/families in need of a palliative care consult	• Well established, high-functioning EHR with a large team of Information Specialists	• Create electronic "triggers" to identify patients eligible for PC consults/ongoing visits

Appendix E: Overview of Current State



Palliative Care

- Aims to improve quality of life for patients and families facing serious illness.
- It can help to relieve pain, symptoms and stress, whatever the prognosis.
- It's appropriate at any age and at any stage and can be provided along with curative treatment. *(CAPC, ACS)*

Value

Patients + Families	Clinical Care Teams	Healthcare Systems
Improved quality of life Decreased physical and emotional symptom burden Longer survivial Improved coordination of care Decreased unnecessary or unwanted medical care Earlier access to end-of-life services More informed decision-making Enhanced trust in healthcare providers	Enhanced communication and collaboration among interdisciplinary team members, patients and family Enhanced provision of holistic, patient-centered care Better patient and caregiver outcomes Improved symptom management Increased patient and family satisfaction	Decreased cost: • Less ED visits and admissions • Estimated $1.2 billion annual cost savings over current inpatient utilization • Decreased length of stay • Better utilization of resources Increased provider, patient, and family satisfaction Better provision of evidence-based practice, patient-centered care

70% of Americans are "not at all knowledgeable" about palliative care. Yet 92% of people polled would likely consider palliative care when it was explained. *(ACS)*

70% of healthcare systems have a palliative program

Practice

All clinicians practice palliative medicine. Specialist teams are available to provide support.

	Inpatient	Outpatient
Staffing	Shift: 1 Physician 1 Adv practice Nn 1 Social worker 1 Fellow Total: 4 Physicians 4 APNs Social workers Fellows	Shift: 1 Physician 1 Nurse practitioner 1 Social worker Total: 3 Physicians 2 NPs 3 Social workers 1 Chaplain 1 CAA
Process	***24/7 service*** 1. Receive consult requests from primary teams 2. Open the consult same day as placed 3. Maintain contact with primary team while patient remains in hospital 4. Refer to outpatient team, as appropriate.	***Standard clinic hours*** 1. EPIC referrals + "urgent" day-of referrals 2. New patient: NPC checks on insurance and schedules with outpatient MD/NP team 3. Visit: Within one week of referral; social worker may join visit 4. Ongoing: 1/week or 1/3-month

Find out more at http://lane.stanford.edu/portals/palliative-care.html

Barriers

1) Process

Theme	Representative Quote
Palliative overlap with other supportive services	"I am confused in terms of how to use these programs. We have palliative care...pain clinic...integrative medicine. I have no idea which one to send to." "It would be nice if that was all under one umbrella."
Timing	"The first call is not the time for screening or referral. You haven't made a connection yet, built rapport. You are trying to get them ready for that first appointment." "I think it's pretty variable. In the past, somebody with incurable cancer, you can rely on their life expectancy to be short...that's not going to be uniformly true more and more."
Referral process is: • Unclear • Cumbersome	"The problem is that some people just blankly make referrals, where they don't understand the disease...and that's generally problematic...it's a whole bad game of telephone." "The logistics…took me five phone calls to figure out who the new patient coordinator was…took another five phone calls to try and get the patient seen…I think just making the process of referring them easier."
Scheduling	"Going to another clinic, it's an aggravation, and they're perturbed enough. Having someone say it's available at the heme clinic or available on call would be useful."
Communication between teams	"I've had some pretty direct conversations where I say, "Stop managing them. Are you going to take care of this patient or am I going to take care of this patient because we keep doing this. The communication isn't right. It's getting all messed up."
Lack of capacity	"I mean it's shown by the lung cancer study as early as we can, but right now it just doesn't feel like it's feasible to call them for all of our newly diagnosed metastatic patients." "Is there someone on-call that I can reach out to? Is there a pager? What if there are multiple cases at once? Is there capacity for this?"

2) Perception

Theme	Representative Quote
Palliative medicine is for end-of-life or when there are "no other options"	"That's the problem with most of us. We call palliative care when we have no other options for the patients but we don't call them early on." "It's a very important specialized role in the terminal phase of disease with I just cannot say ... I cannot do anything for this patient." "Even though we may think of palliative care as being symptom control and management...and addressing symptoms related to cancer, patients always hear, "Why is he bringing them up palliative care? Am I going to die?" It is challenging."
Assumption that oncology does not provide palliative	"'Yeah, because I don't give any of my patients supportive care. I just give them chemo.' I think the insult that we all feel about being thought of as either...fry them or run toxins through them but heaven forbid that I should actually acknowledge there's a human being within my bond."
Feeling that separate team is not absolutely necessary	"I think that you don't need a dedicated palliative care physician to provide palliative care to your patient nor should that imply that somehow you're not supposed to be providing palliative care because probably the majority of what we do is actually palliative care."
Confidence in palliative team's level of disease-specific knowledge	"I'll think it will be more useful if they, say, get to know the disease a little better. Like we have for lymphoma, half the patients are cured…"

Appendix F: Evidence Synthesis Table of Reviewed Randomized Control Trials

Study Authors	Year Published	Palliative Care Service or Intervention	Patient Population	Measurement/Assessment Tool	Outcomes
Bakitas et al.	2009	Nurse-led multicomponent, psychoeducational intervention telephone-based approach	Male and female patients with GI, Lung, GU, and Breast cancer	• Functional Assessment of Chronic Illness Therapy for Palliative Care (FACT-PC) • Edmonton Symptom Assessment Scale (ESAS) • Center for Epidemiological Studies Depression Scale (CES-D)	• Improvement in quality of life (P= 0.02) • Improvement in mood (P= 0.02) • Improvement in symptom burden (P=0.06) • No statistically significant variation in resource utilization between groups
Follwell et al.	2009	Referral to palliative care consultation in outpatient setting	Male and female patients with GI, Breast, Lung, Head and Neck, Brain, Gynecologic, Skin, GU, Hematologic, and unknown primary cancers	• Edmonton Symptom Assessment Scale Distress Score (EDS) • Family Satisfaction with Advanced Cancer Care (FAMCARE), patient-adapted version	• Improvement of EDS scores at one week and one week (P values ranging from P<0.0001- P= 0.009) • Improvement of FAMCARE scores at both one and six weeks (P values ranging from P< 0.0001- P= 0.002)
Temel et al.	2010	Palliative care consult with an interdisciplinary palliative care team, which includes: assessment of physical and psychosocial symptoms, goals of care, assisting with decision making regarding treatment, and coordinating care based on needs	Male and Female patients with newly diagnosed non-small-cell lung cancer	• Functional Assessment of Cancer Therapy-Lung (FACT-L) • Lung-cancer subscale (LCS) of the FACT-L • Trial Outcome Index (TOI) • Hospital Anxiety and Depression Scale (HADS) • Patient Health Questionnaire	• Reduction of depressive symptoms (P= 0.01 for HADS-D; P= 0.04 for PHQ-9) • Improved quality of life (P= 0.03) • Clinically significant but not statistically significant improvement in anxiety (P= .66).
Zimmerman et al.	2014	Provision of early palliative care	A variety of advanced	• Functional Assessment of	• At 3-months, there was no

		versus standard cancer care	cancer patients with an European Cooperative Oncology Group performance status of 0–2, and a clinical prognosis of 6–24 months.	Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp) • Quality of Life at the End of Life (QUAL-E) • ESAS • FAMCARE-P16 • Cancer Rehabilitation Evaluation System Medical Interaction Subscale (CARES-MIS)	significant difference in change score for FACIT-Sp between intervention and control groups; there was a significant difference in QUAL-E (p=0.05) and FAMCARE-P16 (p=o.0003), and no difference in ESAS (p=.33) or CARES-MIS (p=0.40). • At 4 months, there were significant differences in change scores for all outcomes except CARES-MIS. • All differences favored the intervention group.
Carlson et al.	2012	Screening with computerized triage or personalized triage following screening for distress	Newly diagnosed cancer patients 18yrs and older with any type of cancer	• Distress Thermometer • Pain numerical rating scale • Fatigue numeric rating scale • Psychological screen for cancer using the PSSCAN Part C • Access to services (asked at 3,6, and 12months by a screening assistant)	• No changes between triage groups in regards to their distress, anxiety, depression, pain, and/or fatigue over the course of the 12-month study period • the group who received personalized triage accessed more services than the computerized group (1,213 services versus 825 services).

Glare et al.	2013	Implementing the screening and referral components of the NCCN Guidelines for Palliative Care	Hospitalized patients admitted to the Gastrointestinal Oncology service	• NCCN Guidelines for 6 palliative care concerns: uncontrolled symptoms, moderate-to-severe distress, serious comorbid conditions, a poor prognosis, patient/family concerns about the course of the disease and treatment decision-making, and patient/family requests for PC	• Screening was feasible as reported by the nurses who screened the patients • Increase in access to Palliative Care • 50% of patients with early stage disease or no disease screened positive due to comorbid illness, poor performance status, and/or had uncontrolled symptoms. • Current criteria may be too sensitive for the inpatient environment given that 64% of patients screened indicated a need for a palliative care consult, but 30% of them were managed by their primary team.

Appendix G: Levels of Evidence Table

	Level 1	**Level 2**	**Level 3**	**Level 4**	**Level 5**	**Level 6**	**Level 7**	**Other**
	Systematic Review or Meta-Analysis	Randomized Control Trial	Controlled Trial without Random-ization	Case control or Cohort study	Systematic Review of Qualitative or Descriptive Studies	Qualitative or Descriptive study	Expert Opinion or Consensus	Review Article
Greer et al. (2013)								**X**
Zimmerman et al. (2014)		**X**						
Teunissen et al. (2007)	**X**							
Follwell et al. (2009)				**X**				
Bausewein et al. (2011)					**X**			
Brasel (2007)								**X**
NIH (2004)							**X**	
Richards et al. (2011)				**X**				
Browner and Smith (2013)	**X**							
Stro¨mgren et al. (2002)				**X**				
Schultheis et al. (2013)				**X**				
Pelayo-Alvarez et al. (2013)				**X**				
Bush et al. (2010)				**X**				
Carlson et al. (2012)		**X**						
Glare et al. (2013)		**X**						
Dudgeon et al. (2008)				**X**				
Seow et al. (2010)				**X**				
Kamal et al. (2013)				**X**				
Khatcheressian et al. (2005)								**X**
Cleeland et al. (2013)								**X**

Appendix H: IRB Exempt from USF

UNIVERSITY OF SAN FRANCISCO | School of Nursing and Health Professions

Student Project Approval: Statement of Determination

Student Name: Alison Morris

Title of Project:

The Integration of Early Palliative Care into Routine Oncology Care: The Use of a Comprehensive Screening Tool

Brief Description of Project:

This evidence-based practice change project seeks to integrate palliative care into routine oncology care in order to deliver high quality, interdisciplinary, patient-centered care. Therefore, this project proposes that every patient who is new to the Stanford Cancer Center be screened prior to his or her first visit by a nurse (multidisciplinary care coordinator) using the Palliative Care Outcomes Scale, a palliative care assessment-screening tool. The score obtained on the tool will be an indicator of their need for a palliative care consult.

A) **Aim Statement:** By December 2015, every new cancer patient entering the Stanford Cancer Center will be initially assessed by a nurse using the Palliative Care Outcomes Scale (POS) in order to improve psychosocial health, physical symptoms, and assess each patient's goals for medical care. Our performance goals are to ensure every patient eligible for palliative medicine will be offered a palliative care consult.

B) **Description of Intervention:** Prior to their first appointment at the Stanford Cancer Center, new patients will be contacted via telephone by a Multidisciplinary Nurse Coordinator who will administer the POS assessment tool. If the patient scores a 20 or greater, they will be offered a palliative care consultation. After their initial consultation, they will continue to be followed by palliative care, in conjunction with their oncologist, every three months thereafter.

C) **How will this intervention change practice?** By integrating palliative care with oncology care early on in a patient's cancer journey, this project serves as a practice model for concurrent health management and operationalizes clinical care guidelines as set out by AHRQ and the American Society of Clinical Oncology. In addition, this intervention provides greater access to palliative care and enhanced coordination of care among an interdisciplinary

Approved: SONHP Leadership Council 7.8.13
Revised: DNP Department Meeting 10.25.13

health care team, under the same roof. This practice change will force a culture shift, and help mitigate the inaccurate perception that palliative care is only for end of life.

In order for this practice change to succeed, there needs to be buy-in from physicians, social workers, advanced practice nurses, nurse coordinators, and other members of the interdisciplinary cancer care team. Therefore, educating these health care team members will be an essential component of receiving buy-in and gaining support. The goal is that this intervention/practice change will lead to greater patient and caregiver wellbeing as well as improve cost savings by decreasing utilization of healthcare resources (e.g. less visits to the Emergency Department or inpatient admissions).

D) Outcome measurements: The POS will be our primary metric. Negotiations are underway as to what additional tool will be used to assess and measure improvement in symptoms and psychosocial health. End goals include:

- To ensure every eligible patient is offered a palliative care assessment;
- To improve symptoms
- To improve psychosocial health
- To improve utilization of healthcare resources (measures will be ED visits, inpatient admissions, ICU stays, etc.)

To qualify as an Evidence-based Change in Practice Project, rather than a Research Project, the criteria outlined in federal guidelines will be used: (http://answers.hhs.gov/ohrp/categories/1569)

☐ This project meets the guidelines for an Evidence-based Change in Practice Project as outlined in the Project Checklist (attached). Student may proceed with implementation.

☐ This project involves research with human subjects and must be submitted for IRB approval before project activity can commence.

Comments:

Approved: SONHP Leadership Council 7.8.13
Revised: DNP Department Meeting 10.25.13

EVIDENCE-BASED CHANGE OF PRACTICE PROJECT CHECKLIST *

Instructions: Answer YES or NO to each of the following statements:

Project Title: The Integration of Early Palliative Care into Routine Oncology Care: The Use of a Comprehensive Screening Tool	**YES**	**NO**
The aim of the project is to improve the process or delivery of care with established/ accepted standards, or to implement evidence-based change. There is no intention of using the data for research purposes.	X	
The specific aim is to improve performance on a specific service or program and **is a part of usual care**. ALL participants will receive standard of care.	X	
The project is **NOT** designed to follow a research design, e.g., hypothesis testing or group comparison, randomization, control groups, prospective comparison groups, cross-sectional, case control). The project does **NOT** follow a protocol that overrides clinical decision-making.	X	
The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does **NOT** develop paradigms or untested methods or new untested standards.	X	
The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does **NOT** seek to test an intervention that is beyond current science and experience.	X	
The project is conducted by staff where the project will take place and involves staff who are working at an agency that has an agreement with USF SONHP.	X	
The project has **NO** funding from federal agencies or research-focused organizations and is not receiving funding for implementation research.	X	
The agency or clinical practice unit agrees that this is a project that will be implemented to improve the process or delivery of care, i.e., **not** a personal research project that is dependent upon the voluntary participation of colleagues, students and/ or patients.	X	
If there is an intent to, or possibility of publishing your work, you and supervising faculty and the agency oversight committee are comfortable with the following statement in your methods section: *"This project was undertaken as an Evidence-based change of practice project at X hospital or agency and as such was not formally supervised by the Institutional Review Board."*	X	

ANSWER KEY: If the answer to **ALL** of these items is yes, the project can be considered an Evidence-based activity that does NOT meet the definition of research. **IRB review is not required. Keep a copy of this checklist in your files.** If the answer to ANY of these questions is **NO**, you must submit for IRB approval.

*Adapted with permission of Elizabeth L. Hohmann, MD, Director and Chair, Partners Human Research Committee, Partners Health System, Boston, MA.

STUDENT NAME (Please print):____Alison Morris _____

Approved: SONHP Leadership Council 7.8.13
Revised: DNP Department Meeting 10.25.13

Signature of Student: _____ **DATE** 8/15/2014

SUPERVISING FACULTY NAME (Please print): _____

Signature of Supervising: : _____ **DATE** 8/13/14

Approved: SONHP Leadership Council 7.8.13
Revised: DNP Department Meeting 10.25.13

Appendix I: PROMIS Tool

Medical Record Number

Patient Name

Addressograph or Label - Patient Name, Medical Record Number

STANFORD HOSPITAL and CLINICS
STANFORD, CALIFORNIA 94305

CLINICS CANCER CENTER WELLNESS SURVEY

Taking care of your physical and emotional health is very important to us. To better address your health needs; please respond to each item by marking one box per row. Once completed, please give this form to a medical assistant. We will review your responses during today's visit and together determine the support you may want or need. If you have completed this survey in the last 30 days and your answers have not changed, please do not fill out the survey and check here. ☐

This survey is not a replacement for a conversation with your health care provider. If you have concerns please contact your health care team.

	Excellent	Very Good	Good	Fair	Poor
In general, would you say your health is….	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, would you say your quality of life is….	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your physical health?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your mental health including your mood and your ability to think?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your satisfaction with your social activities and relationships?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community; responsibilities as a parent, child, employee, friend)	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

15-2876 (4/13)

Medical Record Number

Patient Name

Addressograph or Label - Patient Name, Medical Record Number

STANFORD HOSPITAL and CLINICS
STANFORD, CALIFORNIA 94305

CLINICS CANCER CENTER WELLNESS SURVEY

	Completely	Mostly	Moderately	A little	Not at all
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In the past 7 days…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	None	**Mild**	**Moderate**	**Severe**	**Very Severe**
How would you rate your fatigue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
My life lacks meaning...					
How true was this before your illness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How true is this now, since your illness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

How would you rate your pain on average?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
	No pain										***Worst imaginable pain***

If you would like help with any issue noted above, please write the issue here _____

_____.

Date	Time	Signature	Relationship to Patient	Print Name
		(Patient, or Properly Designated Representative)		

Date	Time	Staff Signature	Print Name

15-2876 (4/13)

Appendix J: Algorithm for Distress Management

PROMIS Wellness Survey
Work flow and algorithm (draft)
PROMIS Assessment Procedure

STEP 1: Determine areas of need, as indicated.

	Excellent	Very Good	Good	Fair	Poor
In general, how would you rate your mental health including your mood and your ability to think?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In the past 7 days…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

STEP 2: Follow up with patient and family for further assessment.

Follow-Up Conversation with Patient

- Ask for permission to talk about PROMIS.
  - Would this be a good time?
  - Is there anyone else you would like present?
- Invite patient to talk about overall concerns.
- Ask for patient to describe answers in yellow or red.
  - I noticed you marked this question as a _____.
  - Can you tell me more about why you ranked this question as _____?
- ID other symptoms or risks that may contribute to emotional distress (e.g., fatigue, pain, overall health)
- Ask about current management of distress or co-morbid conditions; assess whether these are adequate.
- If applicable, inquire about existing support systems (e.g., family, friends, church, existing providers)

STEP 3: Assign patient distress level.

Mild Distress	Moderate Distress	Severe Distress
No or minimal distress via screen and assessment Recent life events indicate "normal" or appropriate response towards loss/change Responses trend toward resolution over time Patient and family express access to sufficient coping support	Distress gets in the way of daily functioning Symptoms not managed by current treatment regime 0-3 additional symptoms (e.g., pain, nausea, fatigue) Risk factors present (e.g., lack of coping skills or support, other social factors)	High level of distress Distress severely impairs daily functioning ≥ 2 consecutive reports of moderate distress ≥ 3 psychosocial answers in moderate distress category ≥ 4 additional symptoms (e.g. insomnia, weight change, fatigue, agitation) Risk factors present Risk of harm to self or others

Updated 7.6.15 3

PROMIS Wellness Survey
Work flow and algorithm (draft)

STEP 4: Discuss follow-up options with patient and family.

	Pathway 1	Pathway 2	Pathway 3
Physical	Proactive symptom education	Proactive symptom education Standard pharmacological treatment or procedure Consider referral to PM (June 2015) or LiveWell for symptom support	*Immediate:* Contact primary APP for immediate symptom management *Follow-up:* Referral/call to palliative medicine (June 2015) or LiveWell
Psychosocial	Preventive care Offer information for symptom support • Social work business card • Psychology business card • Support group	Psychosocial support, education about psychosocial resources Consider call/referral to service line social worker for further assessment and support	*Immediate:* Page service line social worker for immediate assistance *Follow-up:* Referral/call to palliative medicine (June 2015) or LiveWell
ALL PATHWAYS			
○ Discuss "what to expect" during next steps in treatment (e.g., physical symptoms, possible emotional distress) ○ Educate patient/family about treatment for breakthrough distress, medication side effects, and self-management tips. ○ Offer information about support services such as support groups, individual and family counseling, integrative medicine, supportive oncology, and palliative medicine. ○ Suggest contacting MCC if symptoms change. ○ Inform patient and family of ongoing assessment throughout care at Stanford.		

STEP 5: Document that PROMIS screen and assessment has been completed.

(Forced fields)
- PROMIS assessment completed? Y/N
- Actions Taken? (Drop down: None, Psychosocial support, Medication change/procedure, Referral, Crisis Management, Other)

References

Appendix K: Nurse Coordinator Survey

PROMIS Survey

PROMIS Wellness Survey Feedback Questionnaire

The PROMIS Wellness Survey was launched digitally Cancer Center wide on June 8, 2015. The development team wants to make sure screening for patients' psychosocial needs is as efficient and as useful as possible. We need your feedback to improve the process for screening and distress management. Please answer the questions below. It should take **less than 5 minutes to complete**. Thank you!

1. As a screening tool, how effective is the PROMIS Wellness Survey in identifying patients' emotional, physical, and practical needs?

- ◯ Not at all Effective
- ◯ Somewhat Ineffective
- ◯ Not Sure
- ◯ Somewhat Effective
- ◯ Very Effective

Comments about effectiveness:

2. How accurately do you feel the PROMIS Wellness Survey represents patient emotional, physical and practical needs?

- ◯ Not At All Accurately
- ◯ Somewhat Inaccurately
- ◯ Not sure
- ◯ Somewhat Accurately
- ◯ Very Accurately

Comments:

3. How helpful has the PROMIS Wellness Survey been to enabling informed discussions with patients about their emotional, physical and practical needs?

- ◯ Not at all Helpful
- ◯ Somewhat Unhelpful
- ◯ Not Sure
- ◯ Somewhat Helpful
- ◯ Very Helpful

Comments:

4. How often do you open PROMIS Wellness Surveys associated with your patients?

- ◯ Never
- ◯ Rarely
- ◯ Sometimes
- ◯ Often
- ◯ Always

5. How helpful has the PROMIS Wellness Survey been in decreasing barriers to appropriate referrals to other services?

- ◯ Not at all Helpful
- ◯ Somewhat Helpful
- ◯ Not Sure
- ◯ Somewhat Helpful
- ◯ Very Helpful

Comments about referrals:

6. How easy is it to navigate through EPIC to identify "unanswered questionnaires" and facilitate patient completion of the PROMIS Wellness Survey?

- ◯ Very Difficult
- ◯ Somewhat Difficult
- ◯ Not Sure
- ◯ Somewhat Easy
- ◯ Very Easy

Please tell us why you gave this ranking:

7. How easy is it to navigate through EPIC to access the PROMIS Wellness Survey responses?

- ◯ Very Difficult
- ◯ Somewhat Difficult
- ◯ Not Sure
- ◯ Somewhat Easy
- ◯ Very Easy

Please tell us why you gave this rating:

8. How clear are the steps for following up on a need identified through the PROMIS Wellness Survey?

- ◯ Not at all Clear
- ◯ Somewhat Unclear
- ◯ Neutral
- ◯ Somewhat Clear
- ◯ Very Clear

Comments about follow-up to patient responses:

9. How adequate was the training you received in enabling you to utilize the PROMIS Wellness Survey and access resources to meet patients' emotional, physical and practical needs?

- ◯ Not at all Adequate
- ◯ Somewhat Inadequate
- ◯ Not Sure
- ◯ Somewhat Adequate
- ◯ Very Adequate

Comments about training:

10. From the list below, please indicate if any of the following (you may select more than one) are outcomes you expect to find as a result of the PROMIS Wellness Survey?

- [ ] Improved patient psychosocial outcomes
- [ ] Improved physical symptom management
- [ ] Better understanding of patient needs
- [ ] Improved communication with patients
- [ ] Improved coordination of care between oncology and specialist services
- [ ] More efficient visits
- [ ] Greater patient satisfaction
- [ ] Greater staff satisfaction
- [ ] More structured workflow around managing patient care needs

Other (please specify)

Done

Appendix L: Survey for Medical Assistants

PROMIS Survey - MA Staff

PROMIS Wellness Survey Feedback Questionnaire

The PROMIS Wellness Survey was launched digitally Cancer Center wide on June 8, 2015. The development team wants to make sure screening for patients' psychosocial needs is as efficient and as useful as possible. We need your feedback to improve the process for screening and distress management. Please answer the questions below. All answers are anonymous. It should take **less than 5 minutes to complete**. Thank you!

1. How easy is it to identify "unanswered questionnaires" in EPIC?

- ◯ Very Difficult
- ◯ Somewhat Difficult
- ◯ Not Sure
- ◯ Somewhat Easy
- ◯ Very Easy

Please tell us why you gave this ranking:

2. How easy is it to help patients complete the PROMIS Wellness Survey in EPIC?

- ◯ Very Difficult
- ◯ Somewhat Difficult
- ◯ Not Sure
- ◯ Somewhat Easy
- ◯ Very Easy

Please tell us why you gave this ranking:

3. How easy is it to view the PROMIS Wellness Survey responses in EPIC once a survey has been completed?

- ◯ Very Difficult
- ◯ Somewhat Difficult
- ◯ Not Sure
- ◯ Somewhat Easy
- ◯ Very Easy

Please tell us why you gave this rating:

4. How clear are the steps for following up on a need identified through the PROMIS Wellness Survey?

- ◯ Very Unclear
- ◯ Somewhat Unclear
- ◯ Not Sure
- ◯ Somewhat Clear
- ◯ Very Clear

Comments about follow-up to patient responses:

5. How helpful was the training you received in showing you how to access the PROMIS Wellness Survey and escalate needs to other members of the clinical team?

- ◯ Very Inadequate
- ◯ Somewhat Inadequate
- ◯ Not Sure
- ◯ Somewhat Adequate
- ◯ Very Adequate

Comments about training:

Done

Powered by

Appendix M: One-Page PROMIS Pamphlet—For Staff

PROMIS Wellness Survey: The Basics

What is PROMIS?

PROMIS is a validated screening tool developed and tested by the National Institutes of Health (NIH) to report on physical, emotional and social wellbeing.

PROMIS is a starting point for conversations about what patients are able to do and how they feel. The tool provides a standard way to collect information about patient needs and health outcomes and track them over time.

Benefits of PROMIS

- Early identification of patients at risk for significant distress
- Ability to better identify and alleviate physical, emotional, and social distress for patients, in general.
- Ability to better identify appropriate referrals to specialty services
- Improved physical, social and emotional outcomes
- Improved ability to provide patient-centered care

Steps to Access and Document PROMIS

1. From the Clinic Schedule, add "Wellness Survey" to the toolbar. Select patient to review responses.
2. Share information with others on the care team.
3. Talk with patients about PROMIS responses to assess needs. In the case of severe distress, consider referral to palliative medicine.
4. Use the dot phrase ".PROMISEQNR" to pull survey results into visit note and comment on outcomes and care plan.

What are the guidelines and evidence behind standard screening for symptoms?

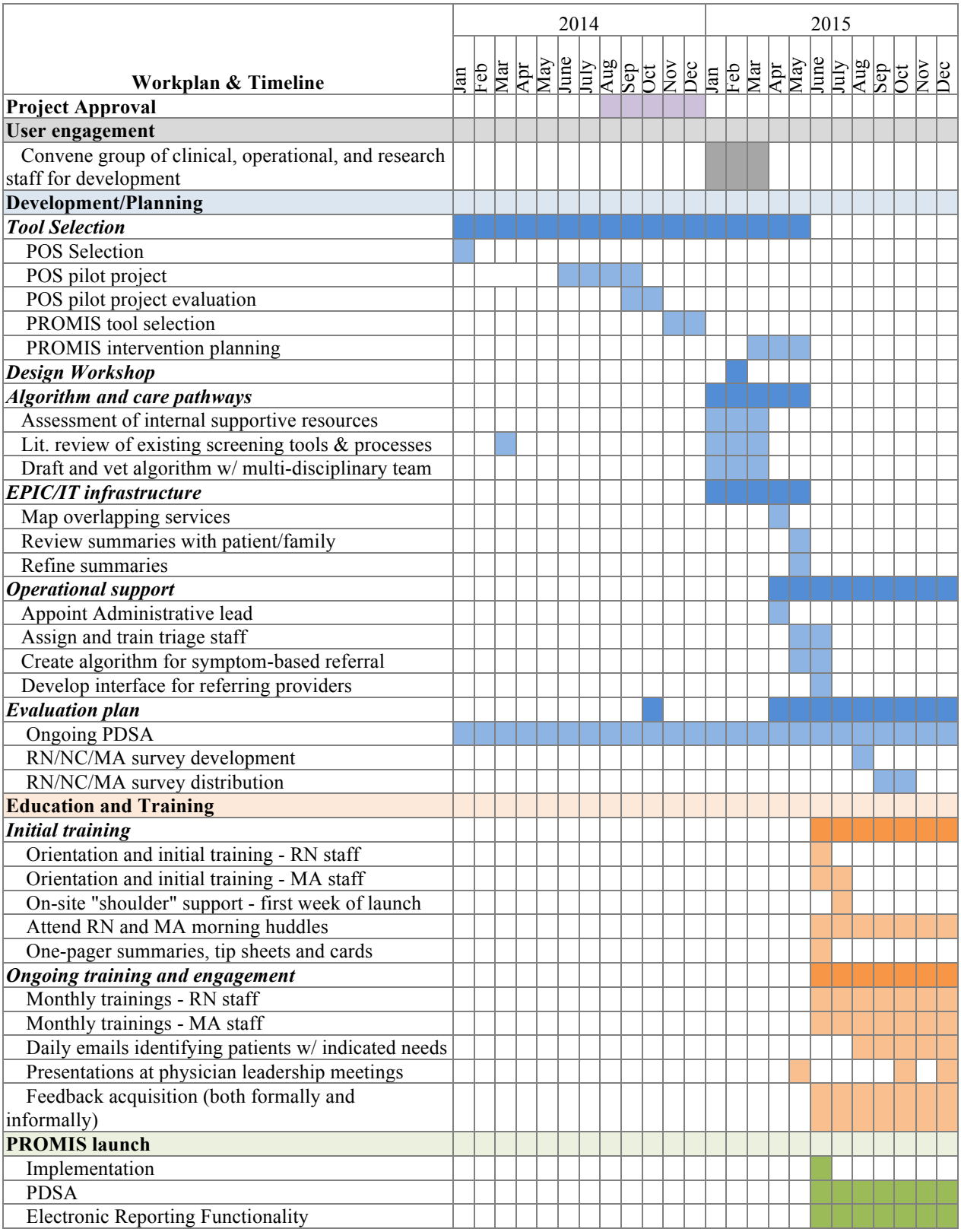
- Early screening and management of symptoms and distress has been shown to improve patient quality of life, coping, and decision-making.
- The Quality Oncology Practice Initiative (QOPI) through the American Society of Clinical Oncology requires all cancer patients be screened for wellness by their second physician visit. Screening and addressing holistic needs early and regularly during treatment is one way Stanford is providing quality patient-centered cancer care.

Questions or concerns: Contact LaTisha Webster at (650) 498-1743 or LWebster@stanfordhealthcare.org. Access EpiCenter for additional instructions.

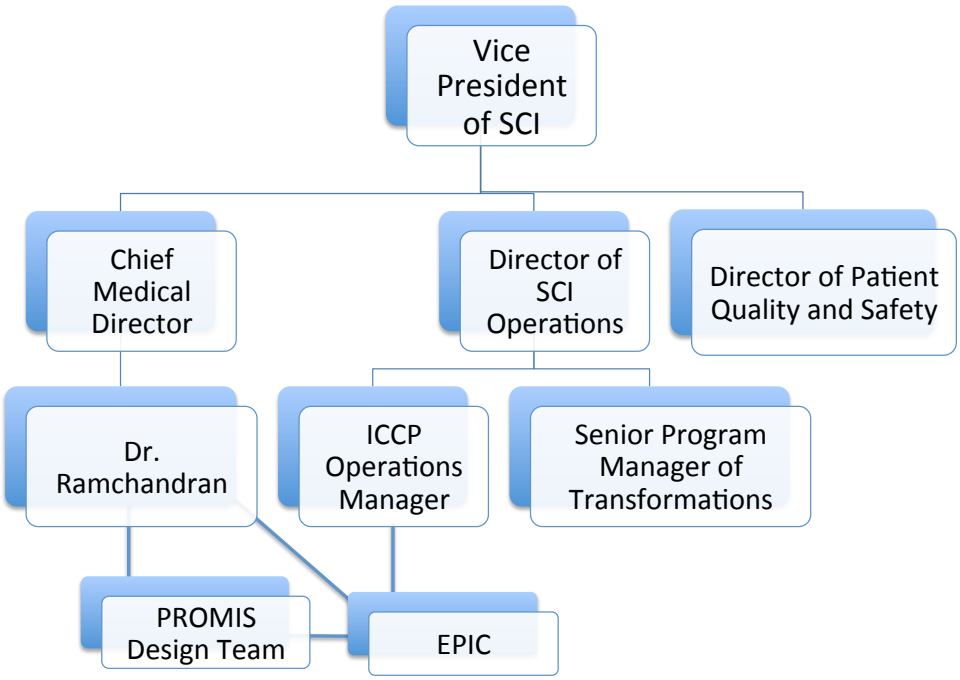
Draft 6.3.15 ET

Stanford MEDICINE

Appendix N: Gantt Chart



Appendix O: Communication Matrix



Appendix P: Percent of Patients with *Relevant Answers*
(8/17/2015-9/30/2015)

% Patients with Identified Need						
CCP	**Week 1**	**Week 2**	**Week 3**	**Week 4**	**Week 5**	**Week 6**
BMT	2.6%	3.8%	1.6%	0.0%	0.0%	7.7%
Breast	2.2%	3.7%	4.0%	6.4%	4.7%	0.6%
Cutaneous	0.9%	23.9%	14.7%	12.0%	15.3%	9.3%
GI	3.9%	0.0%	1.6%	1.3%	2.3%	0.8%
Gyn	4.7%	2.9%	0.0%	4.8%	0.0%	2.4%
H/N	4.8%	6.0%	18.3%	15.1%	16.3%	9.2%
Heme	6.8%	7.3%	1.5%	1.1%	0.0%	0.0%
Lymphoma	0.0%	3.7%	0.0%	0.0%	0.0%	0.0%
Neuro	9.7%	0.0%	3.8%	0.0%	2.6%	5.2%
Rad Onc	0.0%	0.0%	0.0%	6.7%	2.7%	4.3%
Thoracic	1.9%	2.0%	1.1%	0.0%	0.0%	2.3%
Uro	14.1%	2.7%	8.3%	1.6%	6.8%	5.0%
TOTAL (Main)	**4.3%**	**4.3%**	**5.3%**	**4.8%**	**4.4%**	**3.6%**

Appendix Q: Cost/Benefit Analysis

Annual Expense Report

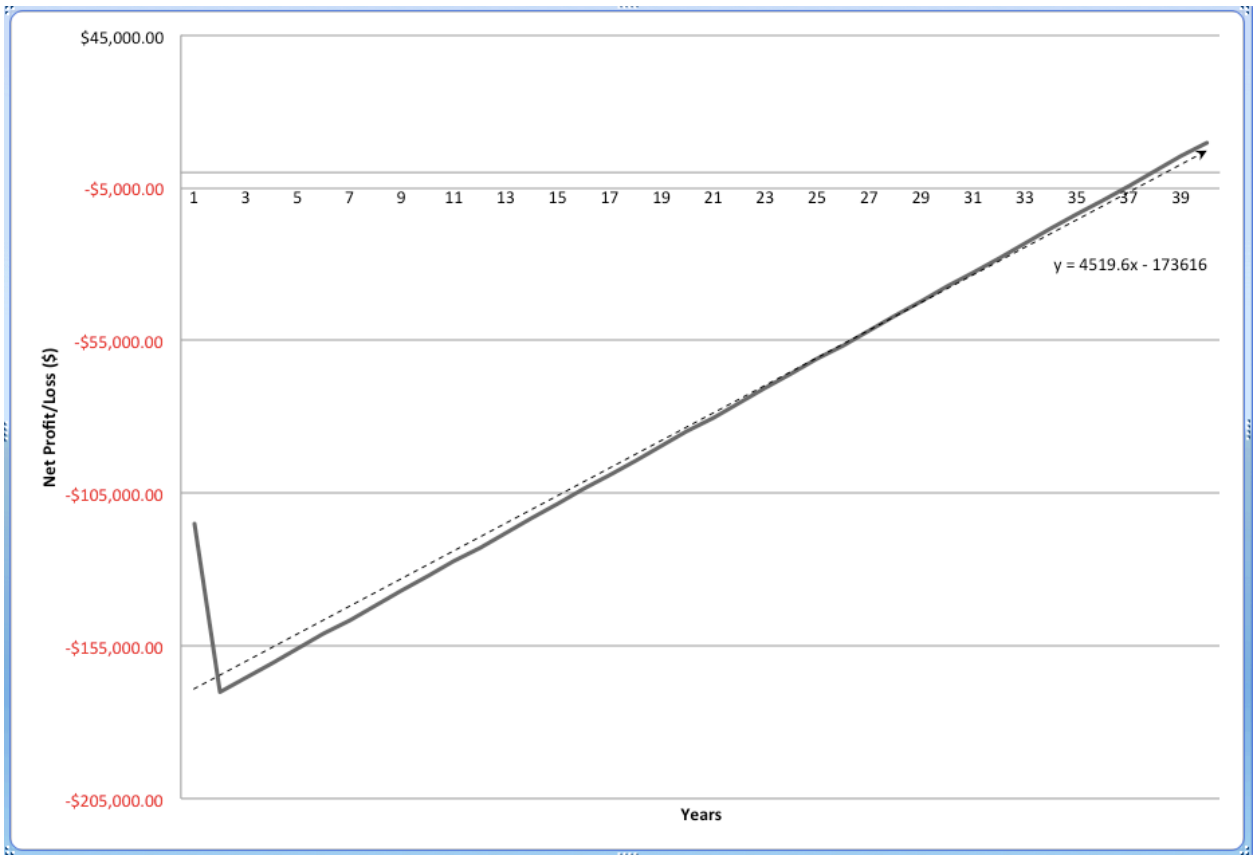
PROMIS	YR 1	YR 2	YR 3
Personnel	($187,125.00)	($127,312.50)	($67,500.00)
Team Lead	($30,000.00)	($15,000.00)	$0.00
Program Designer/Research Assistant	($25,000.00)	($12,500.00)	$0.00
SHC Patient and Family Advisory Council President	($24,000.00)	($12,000.00)	$0.00
Evaluation Specialist	($31,250.00)	($15,625.00)	$0.00
Clinical Informaticist	($9,375.00)	($4,687.50)	$0.00
ICCP Service Center Operations Manager	($30,000.00)	($30,000.00)	($30,000.00)
Assistant to ICCP Service Center Operations Manager	($13,500.00)	($13,500.00)	($13,500.00)
Nurse Coordinator	($24,000.00)	($24,000.00)	($24,000.00)
Training	($315.00)	($315.00)	($315.00)
Copy paper	($15.00)	($15.00)	($15.00)
Printer Ink	($50.00)	($50.00)	($50.00)
Markers	($10.00)	($10.00)	($10.00)
Snacks	($240.00)	($240.00)	($240.00)
Outreach and Marketing	($160.00)	$0.00	$0.00
Copy paper	($10.00)	$0.00	$0.00
Printer Ink	($50.00)	$0.00	$0.00
T-Shirts	($100.00)	$0.00	$0.00
Equipment and Facilities	($3,025.00)	($3,025.00)	($3,025.00)
Conference room: Use and wear	($3,000.00)	($3,000.00)	($3,000.00)
Printer: Use and wear	($25.00)	($25.00)	($25.00)
Subtotal	**($190,625.00)**	**($130,652.50)**	**($70,840.00)**
Supportive Care Services			
Personnel	($43,461.54)	($43,461.54)	($43,461.54)
Palliative Care Physician	($20,192.31)	($20,192.31)	($20,192.31)
Palliative Care Nurse Practitioner	($14,423.08)	($14,423.08)	($14,423.08)
Service Line Social Worker	($8,846.15)	($8,846.15)	($8,846.15)
Subtotal	**($43,461.54)**	**($43,461.54)**	**($43,461.54)**
Estimated Total Annual Expenses	**($234,086.54)**	**($174,114.04)**	**($114,301.54)**

Annual Income Report

Supportive Care Services	YR 1	YR 2	YR 3
New Patient Evaluation & Management Services	$74,400.00	$74,400.00	$74,400.00
MD/APN	$46,800.00	$46,800.00	$46,800.00
New patient visits (annually)	144.00	144.00	144.00
Reimbursable rate per visit	$325.00	$325.00	$325.00
Annual reimbursement	$46,800.00	$46,800.00	$46,800.00
Service Line Social Worker	$27,600.00	$27,600.00	$27,600.00
New patient visits (annually)	138.00	138.00	138.00
Reimbursable rate per visit	$200.00	$200.00	$200.00
Annual reimbursement	$27,600.00	$27,600.00	$27,600.00
Established Patient Evaluation & Management Services	$44,640.00	$44,640.00	$44,640.00
MD/APN	$28,080.00	$28,080.00	$28,080.00
Established patient visits (annually)	144.00	144.00	144.00
Reimbursable rate per visit	$195.00	$195.00	$195.00
Annual reimbursement	$28,080.00	$28,080.00	$28,080.00
Service Line Social Worker	$16,560.00	$16,560.00	$16,560.00
Established patient visits (annually)	138.00	138.00	138.00
Reimbursable rate per visit	$120.00	$120.00	$120.00
Annual reimbursement	$16,560.00	$16,560.00	$16,560.00
Estimated Total Annual Revenue	**$119,040.00**	**$119,040.00**	**$119,040.00**

Return On Investment (ROI)= $119,040/$234,087= 0.508 or 51%.

Appendix R: Breakeven Analysis



Appendix S: Nurse Coordinator Workflow

PROMIS Wellness Survey
Work flow and algorithm (draft)

Overview

Purpose	
Cancer and its treatment impacts the physical, emotional, social, and spiritual wellness in individuals and families experiencing cancer. Symptoms and distress can be complex, pervasive and change dramatically over time. Screening and addressing these concerns early and regularly during treatment at Stanford Cancer Center can help alleviate distress and promote wellness. Establishing an empathic and routine assessment of these needs may promote more meaningful conversations between patients and their care teams about individual needs and goals.	
Owners	
Distribution	MyHealth: EPIC trigger Clinic: MA
Collection	MA
Assessment	MCC/NC
Management	Psychosocial needs: *First line* – service line social work; *Additional specialist* – Palliative Medicine (June 2015); LiveWell (future) Physical needs: *First line* – service line APP/MD *Specialist* – PM (June 2015); LiveWell(future)
Reporting	LiveWell
Timing	
Initial	First return visit
Follow-up	Once every 3 months
Setting	
In-person assessment Dedicated space Dedicated time	
Assumptions	
• Results are easily visible • Administrative "cell" relieves tasks/time if owner is MCC/NC • Dedicated space • Dedicated time (2nd visit and follow-up) • Effective communication between provider and patient/family • Referral and recommendation respected by APPs • Social work has capacity to act as first line response for psychosocial needs • Wellness is a quality measure • Others…	

PROMIS Wellness Survey
Work flow and algorithm (draft)

Procedure Overview
1. Patient completes survey independently (initial survey completed with provider). 2. MCC/NC determines areas for follow-up assessment. 3. Provider assesses need and classifies patient distress level. 4. Provider discusses physical and psychosocial support options with patient and family. 5. Provider makes call or referral to: ○ *Psychosocial* ▪ Service line social work ▪ PM/LiveWell ○ *Physical* ▪ Service line APP ▪ PM/LiveWell 6. Provider documents completion of assessment and specific follow-up note. 7. Follow-up with patient within XX timeframe.

Appendix T: Anticipated Outcomes Table

[Paper] Section	Measure	Comments
Anticipated Outcome	Improved coordination of care	Not easily measurable. Moderating variable to end goals. See end goals.
Anticipated Outcome	Enhanced ability of patients/families to identify and express care needs	Not easily measurable. Moderating variable to end goals. See end goals.
Anticipated Outcome	Normalization of asking about patient well being [for clinicians]	Not easily measurable. Moderating variable to end goals. See end goals.
Anticipated Outcome	Enchanced attention to well-being during clinic visits and incorporation into treatment plans	Not easily measurable. Moderating variable to end goals. See end goals.
Anticipated Outcome	More appropriate and timely access to supportive care services	Not easily measurable. Moderating variable to end goals. See end goals. See also Metric "…referred to supportive care services."
Anticipated Outcome	Standardized procedures and protocols for identification of patients in distress, referral criteria, and follow-up documentation	Not easily measurable. Moderating variable to end goals. See end goals. See also *Administrative/Program Development costs.*
Anticipated Outcome	Increased referrals to supportive services	See *Metric* "…referred to supportive care services."
Anticipated Outcome	Standardized roles and trained personnel who hold referral responsibility	See *Administrative/Program Development costs.*
Aim	Every cancer patient screened by second visit with PROMIS	See *Metric* "Number of patients who receive a PROMIS questionnaire."
Performance Goal	Ensure patients with supportive care needs (*relevant answers*) are addressed and/or referred	See *Metric* "…addressed by their oncology team." and "…referred to supportive care services."
Metrics	Number of patients who receive a PROMIS questionnaire	No cost or benefit to this metric. PROMIS is patient self-administered. Cost was on development of tool and is captured in *Administrative/Program Development costs*. Anticipated benefit is articulated in *End Goals.*
Metrics	Number of patients who complete a PROMIS questionnaire	No cost or benefit to this metric. PROMIS is patient self-administered. Cost was on development of tool and is captured in *Administrative/Program Development costs*. Anticipated benefit is articulated in *End Goals.*
Metrics	Number of patients with identified needs	Identification of needs requires manual review by RN of completed PROMIS tool and subsequent follow-up and management. This is a cost.

Metrics	Number of patients with identified needs addressed by their oncology team	No cost or benefit to this metric. Addressing identified needs is included in a standard reimbursable evaluation and management encounter and does not require additional non-reimbursable services. Benefit: Addressing identified needs is a moderating variable to end goals. See end goals.
Metrics	Number of patients with identified needs referred to supportive care services	No cost or benefit to this metric. Referring to supportive care services is included in a standard reimbursable evaluation and management encounter and does not require additional non-reimbursable services. Benefit: Referring to supportive care services is a moderating variable to end goals. See end goals.
Metrics	Number of patients with identified needs seen by the referred party	No cost or benefit to this metric. Seeing the patient is included in a standard reimbursable evaluation and management encounter and does not require additional non-reimbursable services. Benefit: Seeing the patient is a moderating variable to end goals. See end goals.
Metrics	[Survey] Number of patients who report that their care team asked about their physical, spiritual, emotional and social needs	
Metrics	[Survey] Number of patients who report that their treatment plan considered those needs	
Metrics	[Survey] Number of patients who report that their care team discussed with them how cancer and treatment would impact daily activities	
Metrics	[Survey] Number of patients who report that their care team delivered whole person care	
End Goal	Improvement in symptoms and psychosocial health	The End Goal metric costs are unknown to this author. However, given that SHC is a tertiary care facility whos revenue is based in the provision of reimbursable services, any metric which aims to reduce the provision of such services results in a net cost to SHC. Despite the loss to SHC, all other stakeholders (e.g., consumers, payors/insurers, tax payers [funding state/federal health care programs], etc) benefit from the any attainment of this goal.
End Goal	Decrease ED visits	
End Goal	Decrease inpatient admissions	

Appendix U: SWOT Analysis

STRENGTHS

- No selection bias
- No additional expenses
- Provides more appropriate, timely access to supportive care services
- In accordance with QOPI guidelines and other national organization recommendations (ASCO, CAPC, NCCN, NIH)
- Supportive care services already in place
- Exemplifies an integrative model of palliative care and oncology care
- Fosters active patient and family participation in plan of care
- PRO screening aids in more efficieient monitoring of patient symptoms and treatment response over time
- Proactive patient care planning
- Better utilization of resources

WEAKNESSES

- Many clinicians do not feel prepared to address supportive care needs or psychosocial issues
- Time constraints; charting responsibilities; patient volume
- Busy work environment
- No standardized referral algorithm in place
- Clinician bias blocking screening and/or referral
- Only administered in English
- Unable to pilot project prior to implementation
- Supportive care services already in place
- Exemplifies an integrative model of palliative care and oncology care
- Fosters active patient and family participation in plan of care
- PRO screening aids in more efficient monitoring of patient symptoms and treatment response over time

OPPORTUNITIES

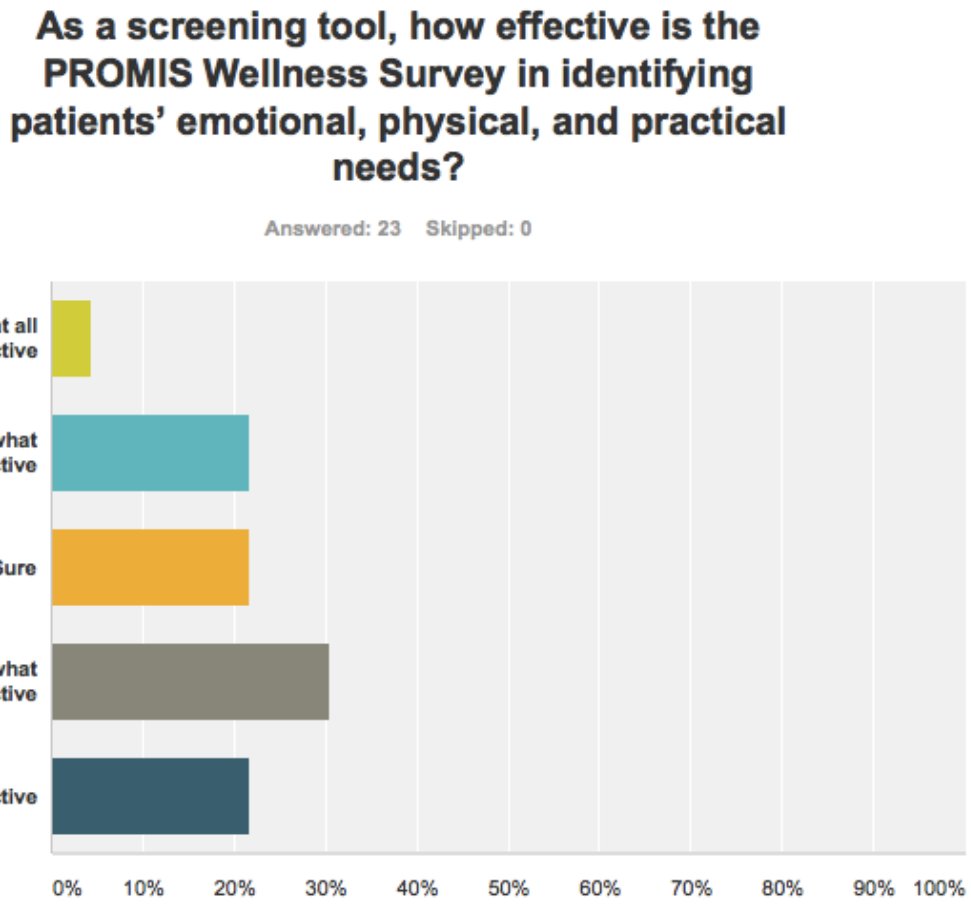
- To identify and address comprehensive care needs early
- To use electronic clinical decision making tools to enhance patient care
- Improved coordination of care; defragment care
- To provide information of impact of PROS on QI, transparency, accountability, public reporting, improved system performances, and impact on health outcomes
- Enhance rapport and communication between patients/families and clinicians
- Improved symptom management
- Improved QOL
- Change in culture and perceptions around palliative care and psychosocial health
- Integration of palliative care into routine oncology clinical practice
- More informed decision making
- Standardized assessment tool
- Decrease ED visits and hospital admissions
- Better allocation of resources

THREATS

- Limited training in how to ask and respond to questions about distress
- Lack of clinician engagement
- Patient and clinicians negative perceptions of the usefulness of screening
- Misconceptions and misunderstanding of palliative and supportive care
- Patients with low literacy, language barriers, visual or physical impairments are more difficult to engage via screening
- Time/Workload
- Role definition
- Fear and anxiety
- Stakeholder buy-in
- Underdeveloped operational infrastructure

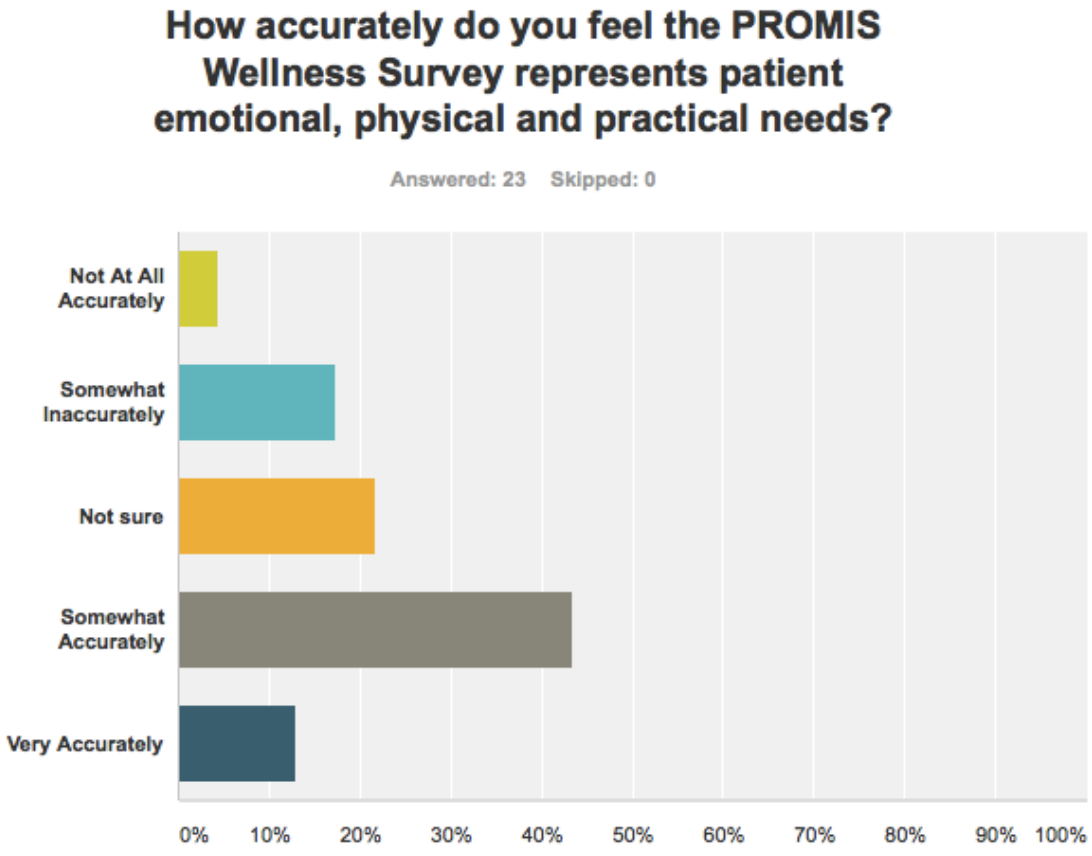
Appendix V: Breakdown of Nurse Responses by Question

Question 1



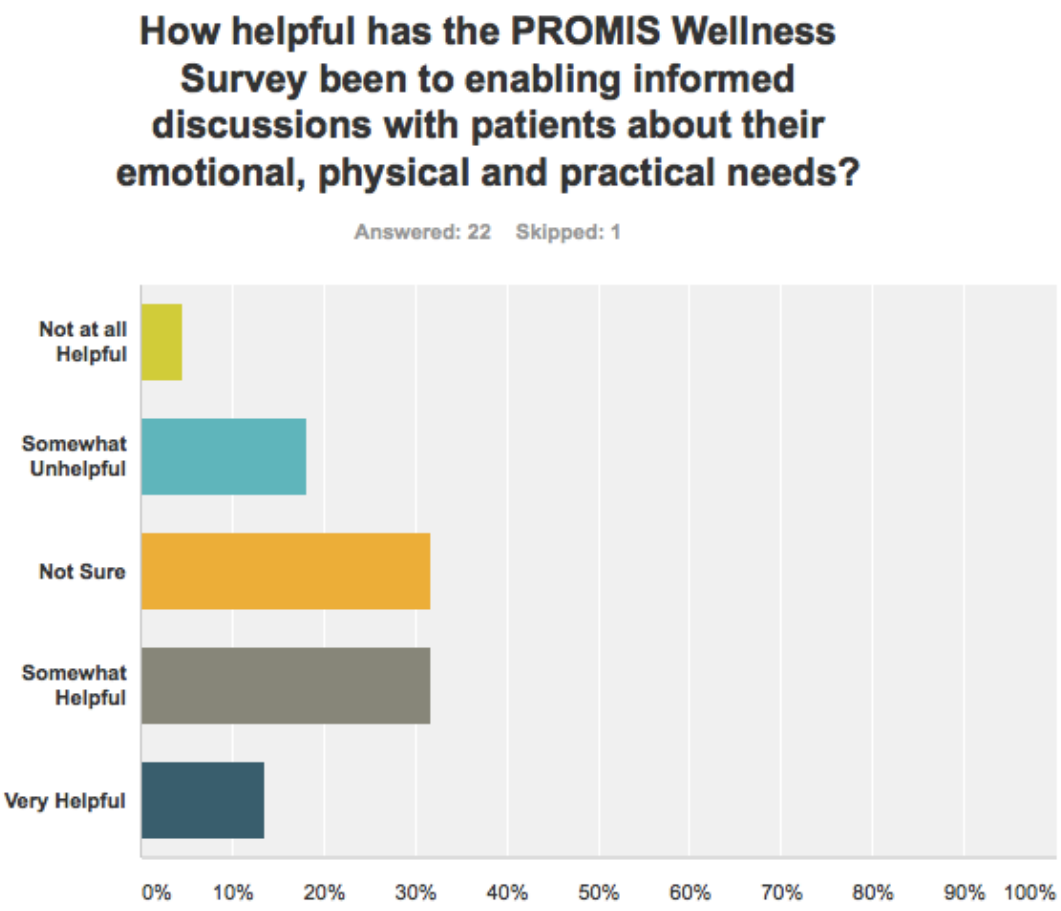
Answer Choices	Responses	
Not at all Effective	4.35%	1
Somewhat Ineffective	21.74%	5
Not Sure	21.74%	5
Somewhat Effective	30.43%	7
Very Effective	21.74%	5
Total		23

Question 2



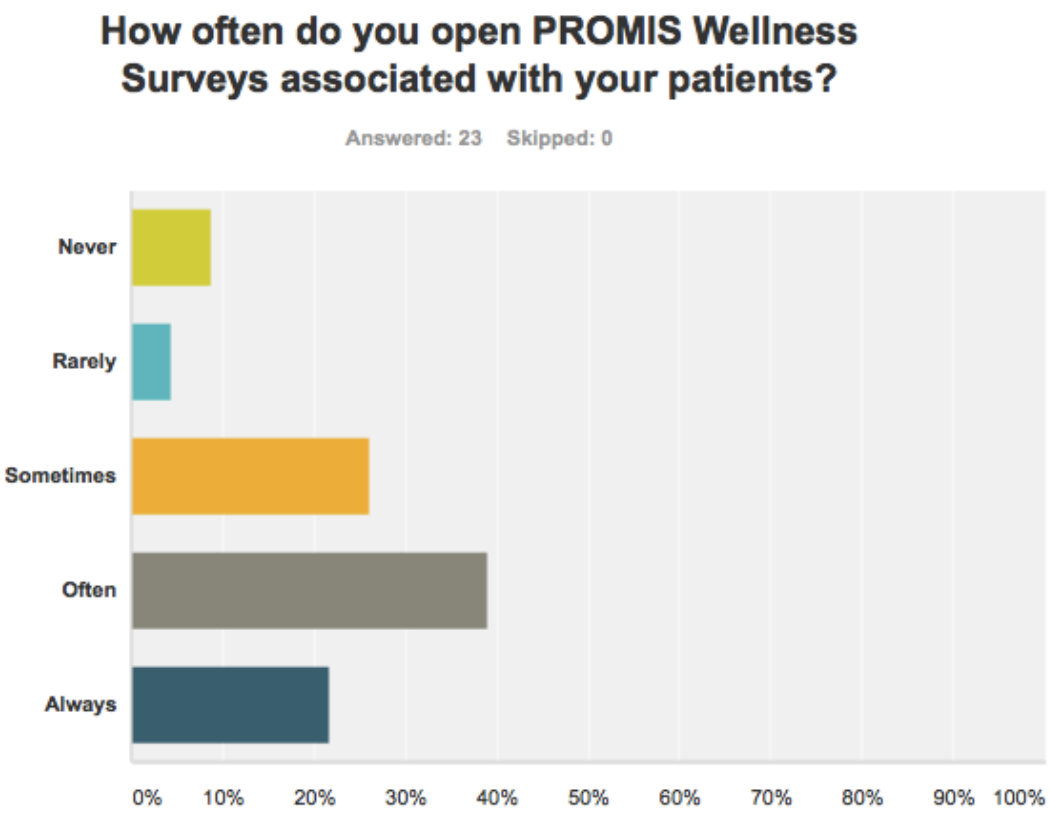
Answer Choices	Responses	
Not At All Accurately	**4.35%**	1
Somewhat Inaccurately	**17.39%**	4
Not sure	**21.74%**	5
Somewhat Accurately	**43.48%**	10
Very Accurately	**13.04%**	3
Total		23

Question 3



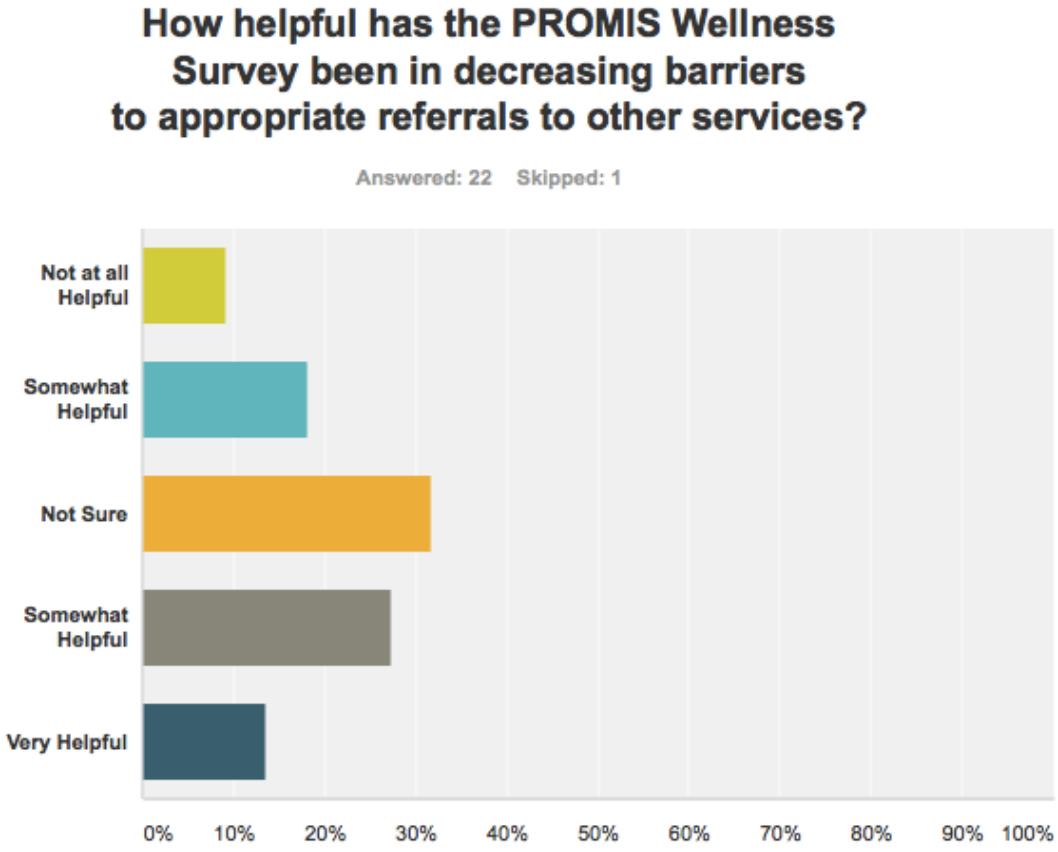
Answer Choices	Responses	
Not at all Helpful	4.55%	1
Somewhat Unhelpful	18.18%	4
Not Sure	31.82%	7
Somewhat Helpful	31.82%	7
Very Helpful	13.64%	3
Total		22

Question 4



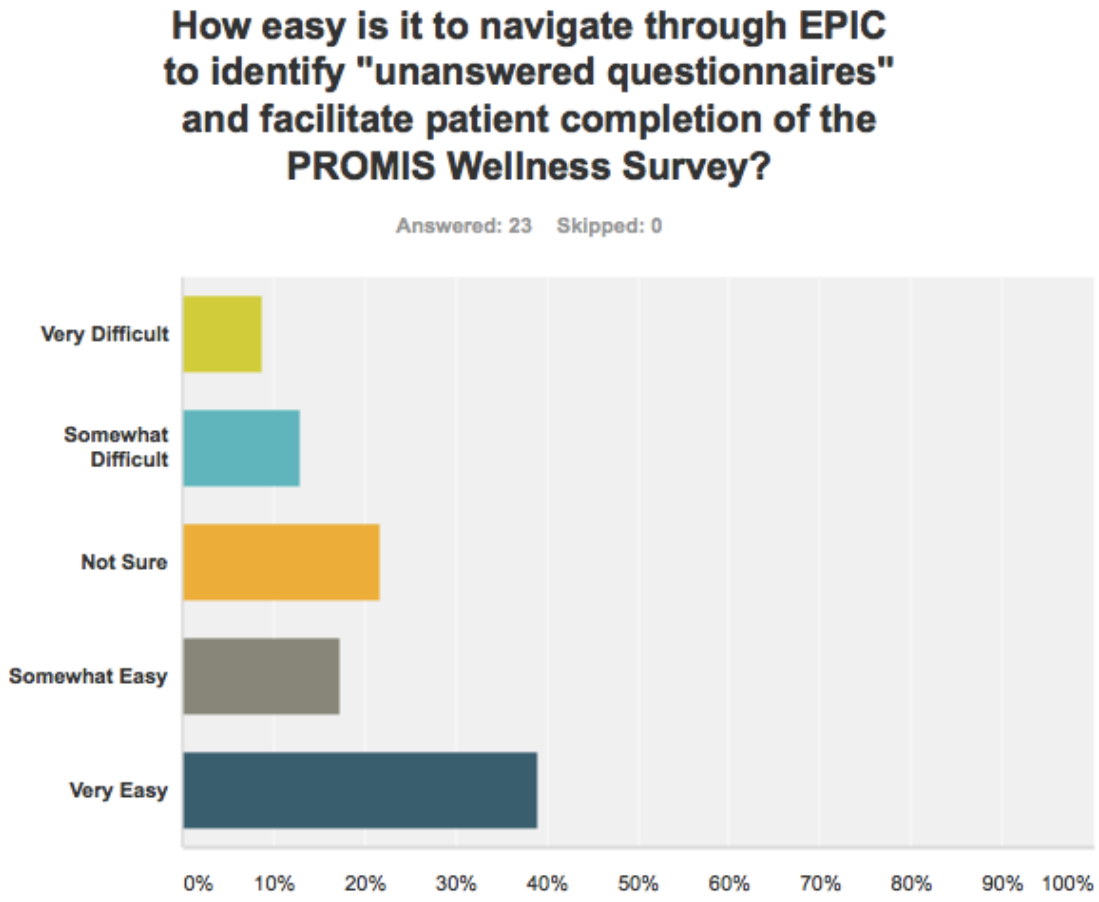
Answer Choices	Responses	
Never	8.70%	2
Rarely	4.35%	1
Sometimes	26.09%	6
Often	39.13%	9
Always	21.74%	5
Total		23

Question 5



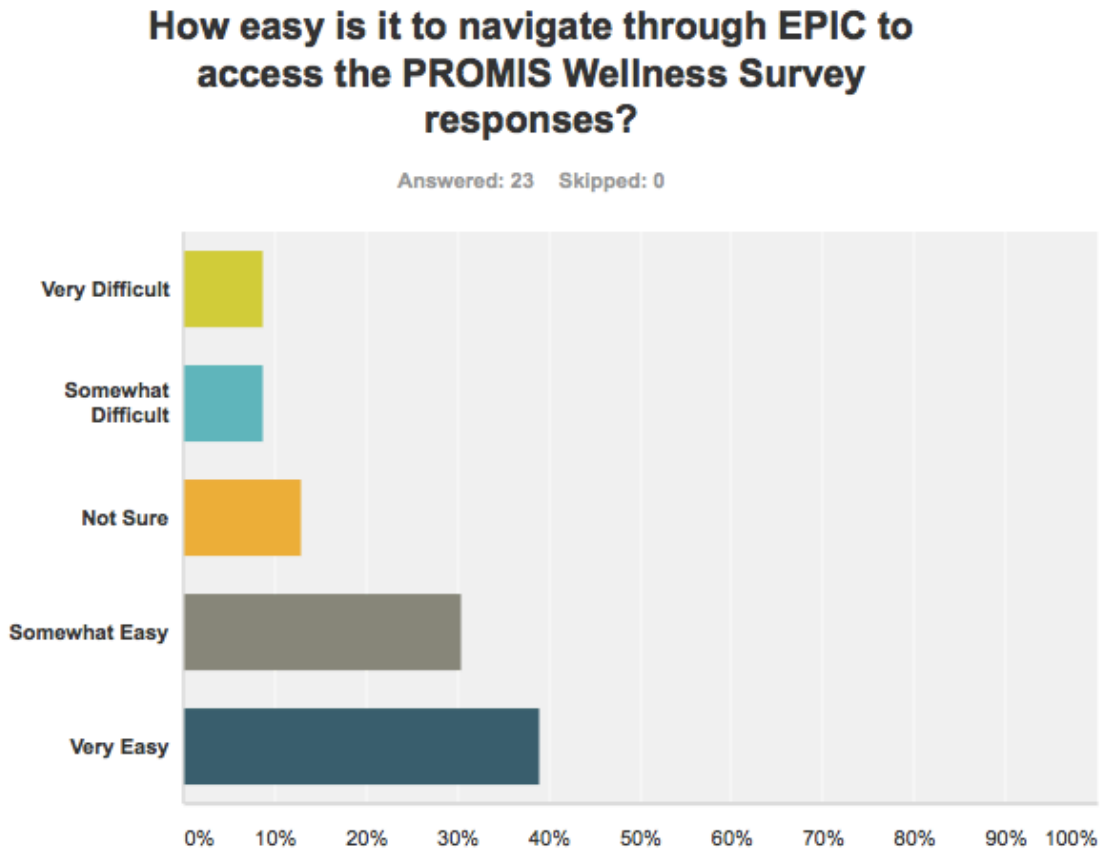
Answer Choices	Responses	
Not at all Helpful	**9.09%**	2
Somewhat Helpful	**18.18%**	4
Not Sure	**31.82%**	7
Somewhat Helpful	**27.27%**	6
Very Helpful	**13.64%**	3
Total		22

Question 6



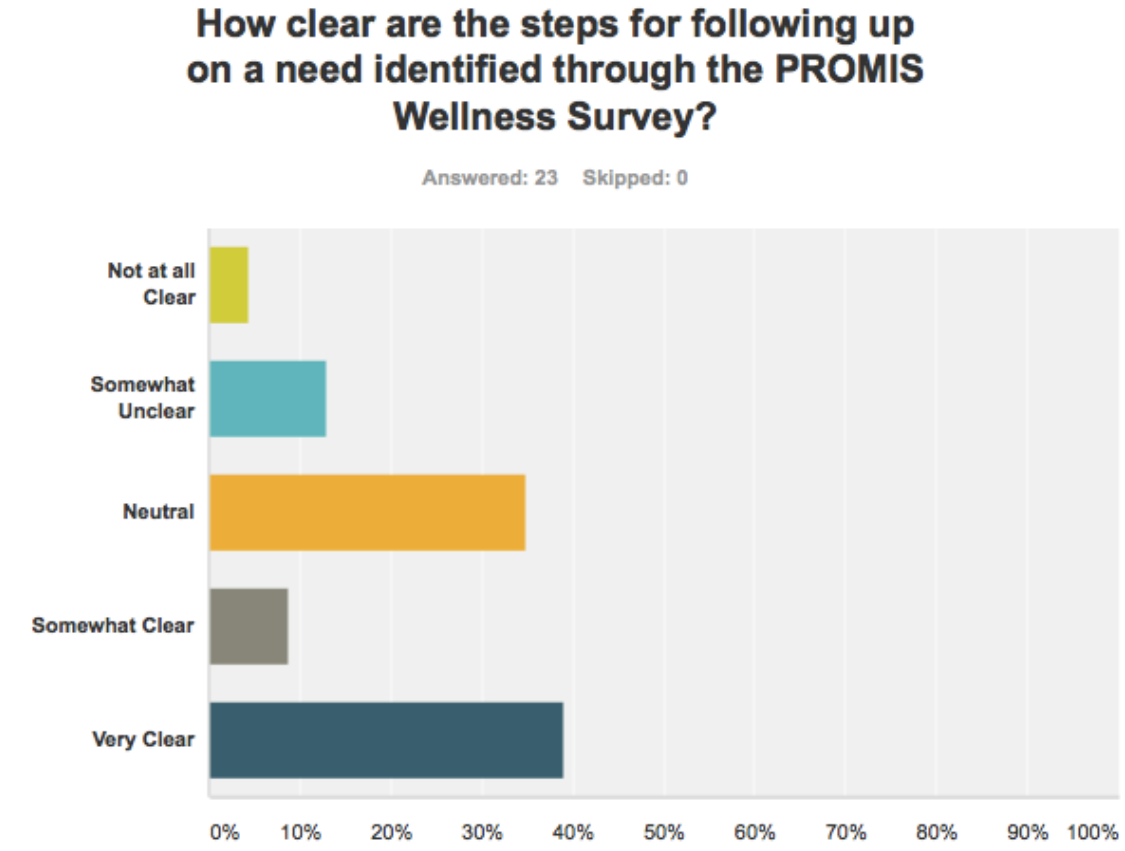
Answer Choices	Responses	
Very Difficult	8.70%	2
Somewhat Difficult	13.04%	3
Not Sure	21.74%	5
Somewhat Easy	17.39%	4
Very Easy	39.13%	9
Total		23

Question 7



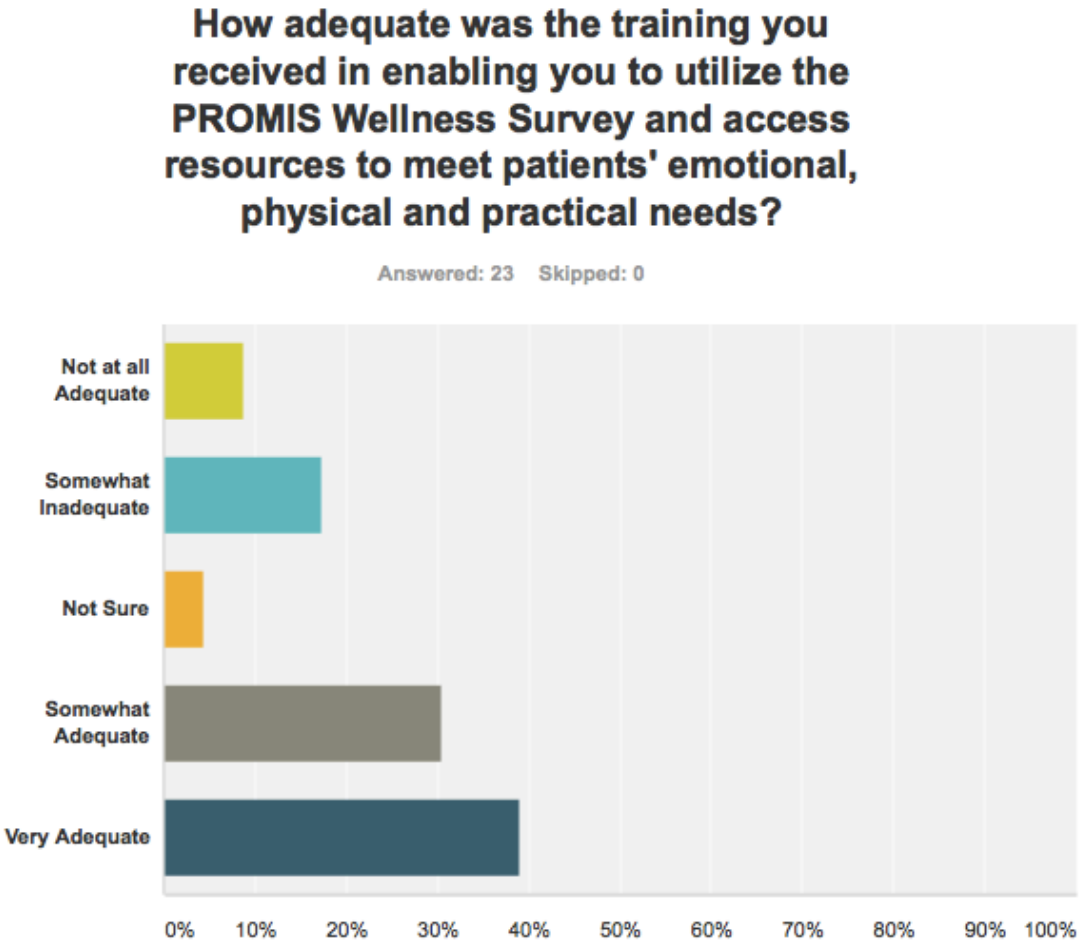
Answer Choices	Responses	
Very Difficult	8.70%	2
Somewhat Difficult	8.70%	2
Not Sure	13.04%	3
Somewhat Easy	30.43%	7
Very Easy	39.13%	9
Total		23

Question 8



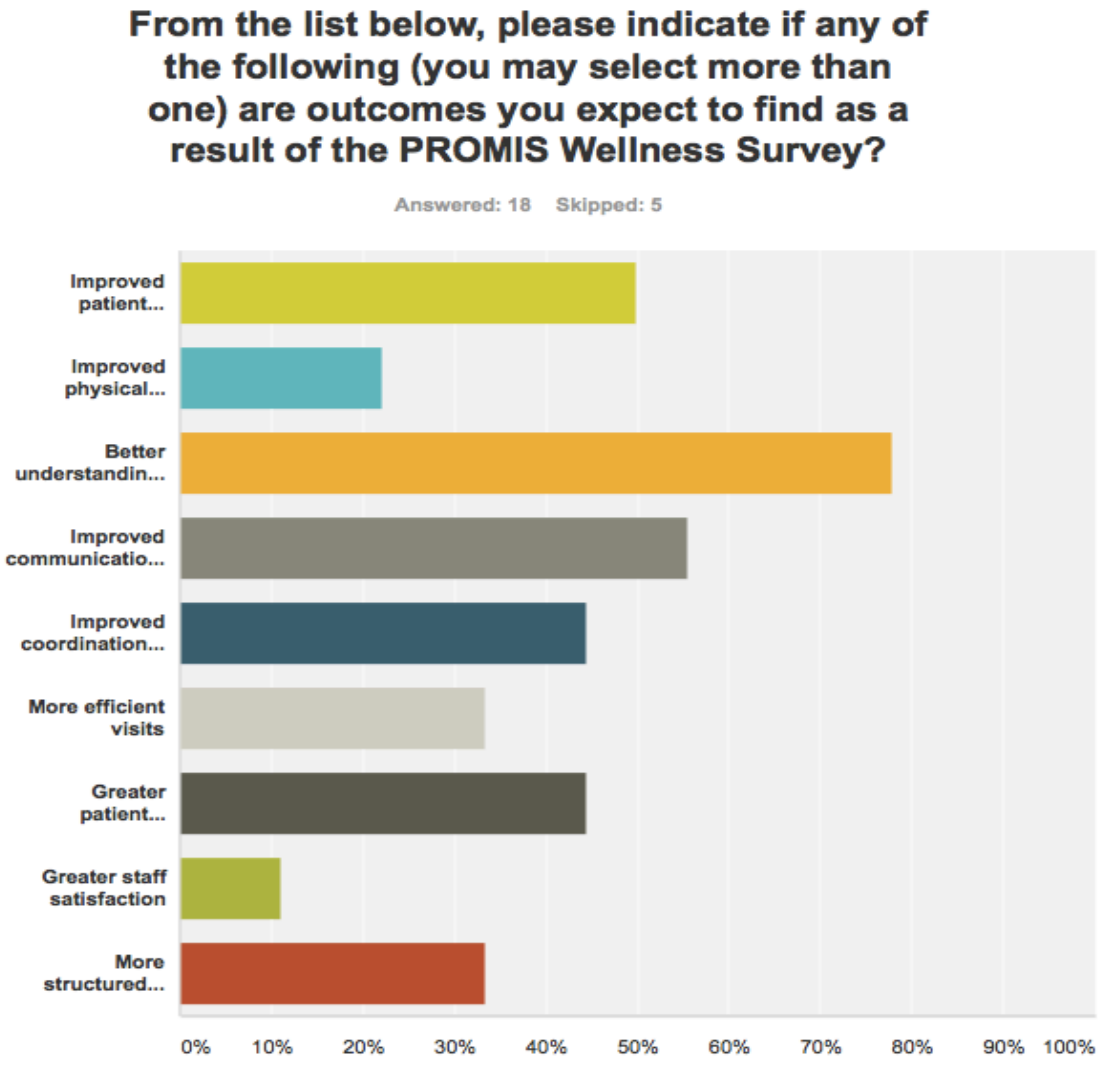
Answer Choices	Responses	
Not at all Clear	4.35%	1
Somewhat Unclear	13.04%	3
Neutral	34.78%	8
Somewhat Clear	8.70%	2
Very Clear	39.13%	9
Total		23

Question 9



Answer Choices	Responses	
Not at all Adequate	8.70%	2
Somewhat Inadequate	17.39%	4
Not Sure	4.35%	1
Somewhat Adequate	30.43%	7
Very Adequate	39.13%	9
Total		23

Question 10



Answer Choices	Responses	
Improved patient psychosocial outcomes	50.00%	9
Improved physical symptom management	22.22%	4
Better understanding of patient needs	77.78%	14
Improved communication with patients	55.56%	10
Improved coordination of care between oncology and specialist services	44.44%	8
More efficient visits	33.33%	6
Greater patient satisfaction	44.44%	8
Greater staff satisfaction	11.11%	2
More structured workflow around managing patient care needs	33.33%	6
Total Respondents: 18		

Appendix W: Completion Rates for PROMIS by CCP from April-September 2015

Disease Group	April	May	June	July	August	September	Total
BMT	N/A	N/A	9.1%	5.7%	5.6%	3.7%	**5.8%**
Breast	37.3%	12.5%	5.6%	8.8%	7.8%	17.1%	**15.5%**
Cutaneous	N/A	N/A	15.0%	0.0%	20.0%	32.6%	**16.0%**
Gastrointestinal	N/A	N/A	9.8%	4.4%	4.7%	3.7%	**5.3%**
Gynecology	26.0%	10.3%	4.7%	17.5%	13.2%	16.9%	**14.6%**
Head/Neck	N/A	N/A	38.9%	9.9%	18.2%	41.4%	**25.3%**
Hematology	N/A	N/A	12.3%	5.3%	9.0%	3.7%	**8.0%**
Lymphoma	N/A	N/A	4.0%	6.6%	5.1%	4.1%	**4.0%**
Neurology	N/A	N/A	16.1%	2.7%	3.3%	2.9%	**6.0%**
Radiation Oncology	N/A	N/A	7.3%	7.8%	5.4%	6.9%	**6.9%**
Sarcoma	N/A	N/A	0.0%	0.0%	0.0%	0.0%	**0.0%**
Skin Cancer & Melanoma	N/A	N/A	24.5%	2.8%	11.7%	31.7%	**16.8%**
Thoracic	N/A	N/A	6.0%	3.1%	5.9%	4.1%	**4.6%**
Urology	N/A	N/A	3.5%	14.8%	34.2%	21.5%	**19.2%**

Appendix X: Crisis Management for MAs

Medical Record Number

Patient Name

Addressograph or Label - Patient Name, Medical Record Number

STANFORD HOSPITAL and CLINICS
STANFORD, CALIFORNIA 94305

CLINICS CANCER CENTER WELLNESS SURVEY

Page 1 of 2

Taking care of your physical and emotional health is very important to us. To better address your health needs; please respond to each item by marking one box per row. Once completed, please give this form to a medical assistant. We will review your responses during today's visit and together determine the support you may want or need. If you have completed this survey in the last 30 days and your answers have not changed, please do not fill out the survey and check here. ☐

This survey is not a replacement for a conversation with your health care provider. If you have concerns please contact your health care team.

	Excellent	Very Good	Good	Fair	Poor
In general, would you say your health is….	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, would you say your quality of life is….	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your physical health?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your mental health including your mood and your ability to think?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, how would you rate your satisfaction with your social activities and relationships?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community; responsibilities as a parent, child, employee, friend)	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

15-2876 (4/13)

Medical Record Number

Patient Name

Addressograph or Label - Patient Name, Medical Record Number

STANFORD HOSPITAL and CLINICS
STANFORD, CALIFORNIA 94305

CLINICS CANCER CENTER WELLNESS SURVEY

	Completely	Mostly	Moderately	A little	Not at all
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	5	4	3	2	1

In the past 7 days…	Never	Rarely	Sometimes	Often	Always
How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	1	2	3	4	5

	None	Mild	Moderate	Severe	Very Severe
How would you rate your fatigue?	1	2	3	4	5

	Not at all	A little bit	Somewhat	Quite a bit	Very much
My life lacks meaning...					
How true was this before your illness?	1	2	3	4	5
How true is this now, since your illness?	1	2	3	4	5

How would you rate your pain on average?	0	1	2	3	4	5	6	7	8	9	10
	No pain										*Worst imaginable pain*

If you would like help with any issue noted above, please write the issue here _____

_____.

Date Time Signature Relationship to Patient Print Name
(Patient, or Properly Designated Representative)

Date Time Staff Signature Print Name

15-2876 (4/13)

***If any of the highlighted sections are marked by the patient, notify the NC, APP, or physician (depending on your clinic reporting structure) immediately for further attention.**

Appendix Y: NC Tip Sheet for Difficult Conversations

PROMIS Wellness Survey
Discussing Psychosocial Issues

Summary of Tips for Discussing Psychosocial Issues
(Developed by Nurse Coordinator Staff)

Preparing for the Discussion

- Make a list of items you hope to discuss.
- Minimize interruptions.
- Take a deep breath, check in with your emotions, and prepare yourself.
- Sit face-to-face with the patient with an open, relaxed posture.
- Remind yourself to slow down.

Words That Work

Ask Permission	• Would you like to talk about this?
Acknowledge & Normalize	• I can see that this is upsetting to you. • It's okay/understandable that you would feel this way.
Assess Patient Needs	• Have you had thoughts of suicide/ending your life? • Could you tell me more about why you feel this way? • How long have you felt this way? • Have you noticed anything has changed in the recent past? • Who/what do you turn to for support (e.g. family, faith)?
Close the Conversation	• Summarize your next steps before leaving the patient (e.g., social work colleague will call you in the next 48 hours)

Appendix Z: One-Page PROMIS Pamphlet- For Patients

About the Wellness Survey

What is the Wellness Survey?

The Wellness Survey is a way for you to tell us how you are doing with regards to your emotional, physical, and spiritual wellbeing. We will ask you to answer this questionnaire periodically so that we can bring your needs into your plan of care as they change over time.

Why is the Wellness Survey important?

This questionnaire will help us improve your symptoms and support your quality of life. Your responses will help identify and connect you with resources at Stanford Health Care that may best meet your needs.

What to Expect?

Prior to appointment

- If you are a MyHealth user, you will receive the "Wellness Survey" three days before your appointment. Please complete the survey before you arrive for your appointment.
- Once you have finished filling out your questionnaire, your care team will be able to look at your results and use them to help you during your appointment.

During your appointment

- If you are not a MyHealth user, your medical assistant will help you access and complete the "Wellness Survey".
- Your nurse or doctor will use your responses to talk with you about how we can help you feel as good as possible living with your diagnosis.
- You and your nurse or doctor will create a plan that helps you get the support you need.

After your appointment

- If you and your nurse or doctor decide it is appropriate, we will call you to schedule time to follow-up on your plan.
- Periodically, we will ask you to complete the same survey so we can make sure that your changing needs are a part of your plan.

At any point, please feel free to talk with your nurse or doctor about health concerns or needs you have that impact your day-to-day life.

Questions or comments about the Wellness Survey: Contact LaTisha Webster at (650) 498-1743 or LWebster@stanfordhealthcare.org.

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