Cancer Patient Support Call Center

A Program to Inform and Involve Newly Diagnosed Cancer Patients in Their Treatment Decisions

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# Table of Contents

I. Introduction ....................................................................................................................... 3  
   a. Background and Rationale ......................................................................................... 4

II. Literature Review ........................................................................................................... 9  
   a. Introduction .................................................................................................................. 9
   b. Search Strategy ............................................................................................................. 10
   c. Summary & Analysis of Systematic Reviews .............................................................. 11
   d. Summary & Analysis of Program Description and Evaluation .................................. 18
   e. Conclusion .................................................................................................................. 21

III. Program Plan ............................................................................................................... 22  
   a. Program Overview ...................................................................................................... 22
   b. Program Context ......................................................................................................... 23
   c. Program Theory .......................................................................................................... 27
   d. Goals and Objectives ................................................................................................. 31
   e. Implementation Plan ................................................................................................. 33
   f. Sustainability .............................................................................................................. 37
   g. Logic Model .............................................................................................................. 40

IV. Evaluation Plan ............................................................................................................ 41  
   a. Introduction and Rationale ....................................................................................... 41
   b. Study Design and Methods ...................................................................................... 45
   c. Dissemination Plan ..................................................................................................... 48
   d. Evaluation Questions ................................................................................................. 49

V. Discussion ...................................................................................................................... 54

VI. Acknowledgements ..................................................................................................... 56

VII. References .................................................................................................................. 56
I. Introduction

The philosophy of health care has recently shifted away from paternalistic care towards empowering patients to become increasingly informed and involved in their medical decision-making.\(^1,2\) Despite theoretical support from health care agencies and professional organizations, achieving informed, shared decision-making (SDM) between patient and provider is extremely challenging in the current health care system. Numerous barriers exist that prevent providers from engaging in this practice, and inhibit patients’ ability to successfully become informed and involved in medical decision-making.\(^3\)

With these challenges come opportunities for novel, innovative programs to encourage, incentivize, and facilitate the steps needed for successful SDM between an informed, involved patient, and an accommodating provider.\(^4-6\) Programs that perpetuate SDM on both the systematic delivery of health care, as well as the interpersonal level are essential.

The purpose of this Master’s Paper is to plan the organization, implementation, delivery, and evaluation of a program, the Cancer Patient Support Call Center (PSCC), that improves the treatment decision-making process between patients newly diagnosed with cancer and their treating physicians. In collaboration with faculty at the University of North Carolina at Chapel Hill Gillings School of Global Public Health and Dr. Jeff Belkora, at the University of California, San Francisco, we will explore the shortcomings of the current decision-making process that inhibit successful SDM in cancer care and review the literature for interventions that address these shortcomings. We will also assess the rationale, context, and relevant theories for designing and implementing an effective, adoptable, and sustainable program. The goals, objectives of our program will be explicitly stated, and the activities needed to reach these goals and objectives will be outlined. Finally, we will design a plan for evaluating the extent to which
our goals and objectives are being reached while simultaneously developing strategies for modifying the organization and delivery of our interventions to improve the reach, effectiveness, adoption, and maintenance of our program.

**Background & Rationale**

**Existing Data:** Significant research has been done to identify the major shortcomings in cancer management decision-making that hinder patients from making a fully informed decision.

Firstly, patients attempt to collect information about their disease and treatment options from numerous outside sources prior to consultations with their physician in order to better understand their situation and alleviate anxiety.\(^7\) Despite the vast amount of information available through media, Internet and print sources, much of this is of low quality, inaccurate, or out of date, and patients struggle to find concise, understandable, and relevant information.\(^8\) Not surprisingly, prior research has shown that information acquisition is the most common unmet need mentioned by cancer patients.\(^9,10\) In order to become informed participants in the decision-making process, patients need better access to high quality information resources outside of the physician encounter.

Secondly, patients frequently do not have the opportunity to consider their personal preferences regarding treatment options or are unable to effectively communicate them during the consultation.\(^11\) It is essential that physicians solicit patient priorities and treatment preferences because physician and patient often differ in their beliefs about disease\(^12\) and goals of treatment.\(^13\) This patient-centered approach to preference-sensitive decision-making acknowledges that,

“Patients have many priorities in addition to maintaining their health, such as making a living, caring for family, and engaging in leisure activities, and these life activities
frequently involve trade-offs between health, comfort, relationships, and financial well-being.”\(^{14}\) (pg. 1806)

Even if given the opportunity, patients often struggle to convey personal concerns and remember important questions during the consultation, often due to distress and anxiety.\(^5\) As a result, physicians are typically incapable of serving as the perfect decision-making agent for patients and interventions that help physicians become aware of their patients’ personal preferences and encourage patient participation in the treatment decision are absolutely necessary.\(^{15}\)

Thirdly, patients must become involved in the decision-making process to the maximum extent that they feel comfortable. It has been well-studied that cancer patients generally prefer a greater level of involvement in the treatment decision-making process than they currently experience,\(^{16}\) and that patients who feel more involved in this process have a greater sustained level of satisfaction with their decision.\(^{17}\) However, patients’ desired level of involvement in the treatment decision is often variable, unpredictable, and depends on disease severity and level of disability.\(^{18}\) Therefore, the physician must “…avoid predicting their patients’ role preference and start providing patients with an open communication climate that allows them to achieve their desired level of participation during decision-making”\(^{16}\) (pg. 6).

Lastly, patients are often overwhelmed with the amount of information discussed during a consultation. Patients typically perceive physicians as the most valuable, credible, and influential source of information for treatment decision-making,\(^7\) however they frequently struggle to understand the technical language used by physicians and have difficulty remembering what was discussed in the consultation.\(^{19,20}\) As a result, patients may leave consultations feeling confused, anxious, and uncertain about what decisions were made and how to proceed.\(^5\) Interventions are needed to help patients record, organize, and recall the information discussed during the medical encounter for later reference.
Policy Frameworks

Healthy People 2010

Healthy People 2010 is a national disease prevention and health promotion initiative managed by the Office of Disease Prevention and Health Promotion and the US Department of Health and Human Services. This report includes several priorities related to the patient-centered approach to cancer care. On a community level, this framework emphasizes that a healthy community enables people to maintain a high quality of life and productivity by offering access to health care services that focus on both treatment and prevention for all members of the community. Healthy People 2010 “encourages local and State leaders to develop communitywide and statewide efforts that promote healthy behaviors, create healthy environments, and increase access to high-quality health care”.

Objective #1 of Health People 2010 is to “increase life expectancy and quality of life by helping individuals gain the knowledge, motivation, and opportunities they need to make informed decisions about their health”. In addition, Cancer, Health Communication, and Public Health Infrastructure are 3 of the 28 focus areas specifically addressed by Healthy People.

Institute of Medicine (IOM), 2001

In the IOM report entitled “Crossing the Quality Chasm: A New Health System for the 21st Century”, patient-centeredness is defined as one of its six primary objectives for improving the quality of medical care in the 21st century. This report also indicates that the process of SDM reflects four of the ten “simple rules” for redesigning health care. These rules include the customization of medical care based on patients’ needs and values, allowing patients to be a
significant source of control, sharing knowledge and the free flow of information, and promoting evidence-based decision-making.

**National Cancer Institute**

Two reports recently published by the National Cancer Institute (NCI) and the National Institutes of Health (NIH) emphasize the importance of patient-physician communication and SDM in improving health outcomes and satisfaction for cancer patients.\textsuperscript{23, 24} The Outcomes Research Branch (ORB) of the NCI has indicated in its strategic plan that research assessing the delivery and impact of patient-centered communication throughout all aspects of cancer care is a key priority, and “encourages the development of innovative measurement approaches and study designs to help monitor and track the success of communication efforts over the course of the patient, family, and healthcare provider experience”\textsuperscript{25}

**General Health Policy Model (GHPM) - Outcomes Model for Assessing Quality of Health Care**

Dr. Robert M. Kaplan, Professor and Chair of Family and Preventative Medicine at the University of California, San Diego (UCSD), and his colleagues began developing a General Health Policy Model (GHPM) in the 1970’s, which emphasizes the importance of evaluating quality of health care in terms of improvements in quality of life in addition to simply extending life expectancy. The “outcomes model”, as it is referred to, incorporates quality of life considerations by separating health status into distinct components, including life expectancy (mortality), functioning and symptoms (morbidity), preference for observed functional states (utility), and duration of stay in health state (prognosis).\textsuperscript{26} This outcomes model considers the impact of care from the patient’s perspective and encourages a process of SDM between a well-
informed patient and an accommodating provider. The communication of medical uncertainty, including the disclosure of probabilities of benefits and harms of treatments, and the solicitation of patient preferences for outcomes is paramount in this model of care.¹

Kaplan argues that shifting our view of what constitutes successful medical care and adopting this outcomes-based conceptualization of health status may influence national health policy by placing the objectives of health care into a different focus, including how health indicator are described, outcomes are measured, clinical decisions are made, and resources are allocated.²⁶

**Informed Consent Policy Framework**

All states have standards for what constitutes valid informed consent. Half of states rely on physician-based standards, which “require physicians to inform a patient of the risks, benefits, and alternatives to a treatment in the same manner that a ‘reasonably prudent practitioner’ in the field would”, while the remaining states use patient-based standards which “hold physicians responsible for providing patients with all the information on risks, benefits, and alternatives to a treatment that a ‘reasonable patient’ would attach significance to in a treatment decision”.²⁷ (pg. 430) According to King and Moulton (2006), “given the current move in US health policy toward increased consumer responsibility in funding medical treatments, considering whether patients receive sufficient information and decision support to enable them to meaningfully participate in their health care is more imperative than ever”.²⁷ (pg. 431)
II. Literature Review

Introduction

The goal of this review is to systematically examine the literature for evidence pertaining to interventions that promote and facilitate informed, SDM for patients facing cancer treatment decisions. The shared approach to decision-making has gained widespread acceptance as the optimal strategy for making decisions on many aspects of cancer care and is increasingly viewed as an essential component of informed consent for undergoing treatment.\textsuperscript{27, 28} The SDM process promotes informed choices because the physician must fully disclose potential risk and benefits for all possible treatment options and the patient is given the opportunity to share relevant personal information that may affect how they value certain outcomes and side effects of the treatment options.\textsuperscript{29} Together, the physician, patient, and any other family members, friends, or relatives participating in the decision-making process integrate scientific knowledge about treatment efficacy with patient preferences for outcomes and potential side effects to make an informed choice on the best course of treatment.\textsuperscript{1}

In order for SDM to successfully result in informed decisions, the patient must obtain accurate, valid and complete information about potential risks and benefits of all treatment options, adequately understand the tradeoffs for each of these options, and have sufficient opportunity to consider his or her individual preferences in relation to the treatment options and communicate these preferences to the physician. Despite widespread acceptance of the SDM concept, numerous challenges and practical obstacles preclude the widespread adoption of interventions and the implementation of programs that promote this process. It is necessary to systematically review the literature for evidence of successful interventions and programmatic
strategies in order to help design an effective, adoptable, sustainable program plan to improve the quality of decision-making for cancer patients facing difficult treatment decisions.

**Search Strategy**

We conduct a search of PubMed/MEDLINE for meta-analyses, reviews, and evaluation studies using different combinations of the following MeSH terms: “Decision support techniques”, “decision-making”, “patient education”, “patient participation”, “neoplasms”, “tape recording”, “information dissemination”, “health attitudes, knowledge, practice”. We then scan titles of results from related combinations of MeSH terms and major topics for relevance to interventions promoting informed, SDM. Interventions addressing all types of medical decisions are evaluated for relevance, but particular attention is paid to interventions and programs involving cancer patients.

A search of meta-analyses and reviews containing “decision support techniques”, “patient education”, and “patient participation” MeSH terms produces 57 results, including 3 editions of a Cochrane Systematic Review on the role of decision aids in medical decision-making. 16 results are produced by a search of meta-analyses and reviews containing the MeSH terms “information dissemination”, and “patient participation”. Of these results, 1 Cochrane Systematic Review examines interventions before consultations for helping patients address information needs. Among the 29 meta-analyses and reviews containing the MeSH terms “tape recording” and “neoplasms”, we identify 3 editions of a Cochrane Systematic Review on the use of consultation recording or summarizing. 3 additional smaller reviews examining the use of audio recording and other techniques for improving patient recall of medical information during oncology consultations are produced by this search.
A search of evaluation studies under the major MeSH topic “neoplasms” that contains the MeSH term “decision-making” produces 73 results. Only one citation appears to be an evaluation of a program that integrates all three interventions examined by the aforementioned Cochrane Reviews. The reference sections of these evaluations are scanned for additional sources, and cross-referenced with the bibliographies of the previously identified Cochrane Reviews.

**Summary and Analysis of Systematic Reviews:**

A critical appraisal of the three systematic reviews and one program evaluation study is necessary to assess the quality of evidence about the effectiveness of interventions to help patients become informed and involved in the treatment decision-making process. We will summarize the background and study criteria, outcome measures, study methods, outcome results, and analyze each study individually.

**O’Connor et al (2009) – Decision aids for people facing health treatment or screening decisions**

Background and Study Criteria: This Cochrane Systematic Review seeks to evaluate the efficacy of decision aids for people facing difficult, “close call” decisions that require weighing benefits, harms, and scientific uncertainty. This review systematically evaluates published randomized controlled trials (RCTs). The RCTs included in this review are studies of interventions designed to aid in patients’ decision-making by providing information about treatment or screening options and their associated outcomes, as compared to no intervention, usual care, and alternate interventions. A decision aid is defined by this review as an intervention that, at a minimum, provides information on the options and potential outcomes.
relevant to a person’s health status, and implicit methods to clarify values in order to help people make a particular choice. Studies are included only if they involve subjects making actual decisions about either screening or treatment for themselves, for a child, or for an incapacitated significant other. Included studies necessarily demonstrate that the intervention meet the minimum criteria to qualify as a patient decision aid as outlined by the International Patient Decision Aids Standards (IPDAS). Studies are excluded from the review if they focus on decisions regarding lifestyle changes, entry into clinical trials, general advance directive decisions, education programs not geared to a specific decision, or interventions designed to improve adherence to or elicit informed consent regarding a recommended option.

Outcome Measures: This systematic review measures a broad range of outcomes. Primary outcomes include “attributes of the decision” – evidence that the patient decision aids improves how well the chosen decision matches the features that matter most to the informed patient (including knowledge, accurate risk perceptions, and value congruence with chosen option), and “attributes of the decision process” – evidence that the decision aids help patients recognize that a decision needs to be made, know the options, understand that values affect the decision and be clear about the features of each option that matter most, discuss these values with the physician, and become involved in the preferred way. Other primary outcomes measured are decision making process variables including decisional conflict, patient-practitioner communication, participation in decision-making, and satisfaction. Secondary outcomes include behavior (proportion that remained undecided, which option was selected, and adherence to chosen option), health outcomes (health status and quality-of-life, anxiety, depression, emotional distress, regret, and confidence), and healthcare system factors (satisfaction, cost/cost effectiveness, consultation length, and litigation rates).
Methods: The Cochrane Review method for identifying studies involves a thorough search of the major electronic databases, including MEDLINE, Cochrane Central Register of Controlled Trials, CINAHL, EMBASE, and PsycINFO. Search strategies are published in the appendix of the review. Two independent authors scan the titles and abstracts to determine relevance of the study.

Search Results: Of a total of 22,778 citations from the electronic database search, only 1,293 citations focus on people’s decision making, and 130 of these appear to be evaluations of interventions. 64 of these studies do not meet inclusion criteria, and the 66 remaining citations provide data on 55 trials which meet the inclusion criteria for the review.

Summary of Key Outcome Results: This review provides substantial evidence that decision aids significantly improve patients’ knowledge of their condition, options, and probabilities of outcomes, reduce decisional conflict, enhance patient-provider communication, and result in greater satisfaction with the decision and the decision-making process.

Analysis: The results of this review must be interpreted with caution. First of all, the quality ratings of the RCTs included in this review universally suffer from lack of blinding. In addition, the wide variety of contexts for decision-making and the broad array of outcomes measures yield insufficient power for finding differences in many interventions, outcomes, and subgroups. Most importantly, only 7 of the 55 trials involve interventions for treatment of cancer (prostate = 2, breast = 5), and 11 study decision aids for cancer screening (prostate = 8, colon = 3), which greatly limits the applicability of these results to interventions to inform and involve patients with cancer facing treatment decisions.

Taking these limitations into consideration, a Cochrane Systematic Review is arguably the most methodologically sound strategy for assessing multiple studies of an intervention, even
if such heterogeneity exists. This review provides considerable evidence that decision aids provide patients with the intended benefit of improving knowledge and understanding, as well as improving various other patient-centered outcomes, even if a lack of external validity limits our confidence in extrapolating these findings to cancer treatment decisions.

Kinnersley (2009) – Interventions before consultations for helping patients address their information needs

Background and Study Criteria: This systematic review examines the effects on patients, providers, and health care systems of pre-consultation interventions designed to help patients address their information needs during consultations. This review includes only RCTs that enroll patients before “one-on-one” consultations with a health care provider to compare usual care with interventions that directly addressed their information needs. These interventions include encouraging the patient to identify and ask questions, express the amount of information they require, consider how they might express their information needs, overcome barriers to communication, and/or check their understanding of information provided during the consultation.

Outcome Measures: Outcomes are divided in to three major categories, including the consultation process, the consultation outcome, and service outcomes. Within these domains, the most commonly measured outcomes are: question asking, patient participation, patient anxiety, knowledge, satisfaction, and consultation length.

Methods: A thorough electronic search of MEDLINE, Cochrane Central Register of Controlled Trials, EMBASE, PsychINFO, ERIC, CINAHL databases is conducted to obtain sources for this review. All search strategies are published in the appendix of this report. Two
independent authors examine titles and abstracts for relevance. In addition, the authors examine reference lists for further potentially-relevant citations, and contact authors of included studies for information regarding similar unpublished studies. Finally, the authors hand-search the journal *Patient Education and Counseling* for additional studies since it contains the highest proportion of possibly-included studies in publication.

Search Results: 4876 citations are generated from the above-listed search strategy, and 71 citations are identified by review authors for possible inclusion. Additional citations are added from other reviews, additional reading and citations of reviewed articles, and hand searching of *Patient Education and Counseling* to create a final set of 106 citations to be assessed. 71 of these are excluded after the authors browse the articles for relevance, which leaves 35 papers describing 33 studies. The total number of patients randomized in these 33 studies is 8,244.

Summary of Key Outcome Results: Meta-analysis of study results show small but statistically significant increases in question-asking and patient satisfaction in patients receiving interventions compared to usual care. Despite not being statistically significant, patient anxiety is substantially decreased both before and after consultations in the intervention group.

Analysis: While a systematic review is generally accepted as the most thorough and robust method for arriving at conclusions about the effect of an intervention, caution must be taken in interpreting results of this review due to the lack of sufficient information provided in the methods of some of the reports. Despite this potential short-coming, a large body of research is reviewed, all of the studies are RCTs, and general consistency in the results is found across all studies. The increase in question asking is the most significant, direct, and quantifiable effect of interventions before consultations intending to help patients address their information needs. Effects on other outcome measures such as anxiety, patient participation, and knowledge are
more difficult to ascertain due to the variability in assessment and measurement methods used by the studies. As compared to the aforementioned systematic review on decision aids, a larger proportion of the studies (9 of 33) evaluate interventions in the Oncology setting. The findings of this review should be considered substantial evidence of the benefit to the patient of pre-consultation interventions that help patients address their information needs.

Pitkethly (2009) – Recordings or summaries of consultations for people with cancer

Background and Study Criteria: This review evaluates the effects of interventions that help patients with cancer and their family members remember what was discussed during a consultation. Randomized and quasi-randomized controlled trials of both adults and children diagnosed with cancer (and their families) are included in the review. Studies are excluded that do not specifically address patients with cancer or are not controlled trials. The review includes studies that evaluate the effects of audio and/or video recording of the consultation and written summaries of the key points of the consultation.

Outcome measures: This review assesses the effect on information access, use, and understanding (information obtained, recalled, and level of understanding), the health care experience (satisfaction, participation in subsequent consultations, complaints and litigation), and health and well-being (physical and psychosocial health status).

Methods: The studies included in this review were initially searched for in 1999 and subsequently updated in 2003, 2005, 2007 and 2009. The strategy for obtaining sources used in the 2009 version of the review involve a systematic search tailored to each of the following electronic databases: MEDLINE, The Cochrane Library, CINAHL, Dissertation Abstracts, Index to Theses, EMBASE, PsychINFO, AMED, British Nursing Index, SCI-EXPANDED, SSCI, and
Sociological Abstracts. The full search strategy is published in the appendix of the review. Two authors independently assess the relevance of titles, abstracts, and full reports, check bibliographies of selected studies, and contact experts in the field.

Results: 37 potentially relevant studies are produced by the search strategy and considered for inclusion. 21 studies either do not specifically address patients with cancer or are not controlled trials and are therefore excluded after examination of the full text. 16 studies (reported in 24 papers) involving 2,318 participants are included in the final review. 15 of these studies are RCTs, and 1 was a quasi-randomised (sequential) controlled trial.

Summary of Outcome Results: Overall, the majority of participants and their family members found the recordings or summaries of their consultation to be valuable. In the 12 studies that assess utilization of the intervention, between 60% and 100% of participants listened/watched the recording or read the summary at least once after the consultation. The recordings or summaries were used to help inform between 41.5% and 94.4% of family and friends assessed in 9 studies. The majority of studies (5 out of 9) find that patients who received a recording or summary reported better recall of the information discussed in their consultation. While no studies find a statistically significant difference between intervention and control groups in terms of anxiety or depression, 3 studies out of 10 demonstrate a greater level of satisfaction with the consultations among those receiving a recording or summary of the consultation.

Analysis: While several limitations and potential biases exist, this systematic review provides the most robust assessment of the effects of these interventions for helping cancer patients understand and recall what was discussed during a consultation. Biases of the included studies may have occurred in the recruitment of the study participants, the method of
randomization used, lack of blinding of clinicians and outcome assessors and varying levels of patient awareness of the study. Despite these potential biases, which likely shift the results away from the null, the interventions are generally comparable across all studies, and all subjects are participating in a cancer care consultation which strengthens the applicability of the outcome results. This review provides substantial evidence of the benefits of recording or summarizing consultations for cancer patients in terms of information recall after the consultation.

**Summary and Analysis of Program Description and Evaluation:**

Belkora 2008 – Monitoring the implementation of Consultation Planning, Recording, and Summarizing in a breast care center.

Goals and Objectives: The Consultation Planning, Recording, and Summarizing (CPRS) program pilots the integration of the three interventions addressed in the above mentioned Cochrane Reviews into a high volume breast cancer clinic at the University of California, San Francisco (UCSF). The goal of this program is to make newly diagnosed breast cancer patients as informed and involved in the decisions made during their treatment consultation as they want to be. To our knowledge, this is the only program published in the literature that integrates the three decision support interventions (information gathering, question-listing, and consultation recording/summarizing) discussed in the aforementioned Cochrane Reviews into a clinical setting.

The objectives of this program are to improve decision quality from a patient standpoint (decision self-efficacy, decisional conflict) while also evaluating the implementation of the program to figure out how to improve its reach, efficiency, and convenience for patients, physicians, and program staff.
Activities: Within the context of an existing high volume breast care center, 8 schedulers were trained to connect women diagnosed breast cancer patients who are scheduled to see a treatment specialist with 1 of 14 trained pre-medical student interns to provide a fully integrated decision support service in conjunction with their usual treatment consultation over the period of March 1, 2005 and December 31, 2006. These interns provide the patients with information relevant to their particular diagnosis via decision aids, then meet in person with the patients to complete a question-listing SCOPED note\textsuperscript{33} prior to their treatment consultation. Interns type up and print out these question lists and provide a copy to both the patient and the physician for reference during the consultation. Interns accompany the patients in the physician encounter, making a digital recording and summarizing the key points of the consultation which they then provide to the patient after the appointment.

A convenience sample of patients received a questionnaire soliciting measures of decisional self-efficacy (DSE) and decisional conflict scales (DCS) before and after the interventions to evaluate effectiveness of the interventions.

Interviews and focus groups of physician, student interns, and scheduling staff were conducted to evaluate acceptability and find out ways in which the program could be modified to increase volume and improve convenience of intervention delivery, and improve utilization of resources.

Analysis: The evaluation strategy of this program combines both qualitative and quantitative measures that examine effectiveness of program interventions from a patient standpoint, as well as service delivery measures by program staff, interns, and physicians. Overall, only 38 out of the 278 patients (13\%) who received program interventions were approached to complete DSE and DCS surveys due to logistical challenges. All but one of these
women completed the surveys before and after the intervention, indicating that this method of evaluating patient-centered measures is feasible and agreeable to patients. Despite the small proportion of women surveyed, results from the convenience sample convincingly showed significant improvement in DSE and a substantial decrease in DSC following the intervention. Evaluators concluded that this sample provided sufficient evidence of the effectiveness of the interventions.

Qualitative analysis from interviews allowed physicians to express their overall opinion about the CPRS program, ways to improve service delivery logistics, and suggested modifications to question lists and summaries in order to make them more usable for both physician and patient. Interviews of CPRS schedulers helped confirm patients’ generally positive response to being offered an accompanying service. They also contributed to changes in how potential program participants were identified and contacted, thereby improving the utilization of schedulers’ time. Finally, CPRS interns expressed satisfaction with the program and the experience of working closely with patients to help improve decision making, but suggested improvements in the flow of service delivery that would increase efficiency and improve time utilization.

This study confirms the patient-centered benefits and effectiveness of interventions delivered by the CPRS program and help direct continued quality improvement of the program. As a result, the program is fully integrated in to the workflow of the breast care center as an accompanying service offered to newly diagnosed breast cancer patients in a manner that is acceptable to clinic staff, program staff, physicians and patients. While the interventions and subsequent evaluation is limited to breast cancer patients at a breast cancer center, the study
results and program framework suggest a high level of adaptability to various other forms of cancer, particularly prostate cancer, in a variety of care settings.5

**Conclusion**

Three systematic reviews evaluating the merits of decision aids, pre-consultation interventions, and consultation recording/summarizing provide high quality evidence that these interventions improve the process of SDM by helping patients become more informed and involved in the decision-making process. On the other hand, evidence of quantifiable benefit to the patient in terms of decreasing anxiety and depression is lacking. This likely is due to challenges in measuring such subjective outcomes, and the substantial variability in personality type and coping ability among people with the same condition who are exposed to the same interventions. Despite various limitations that call the internal validity of these reviews into question, Cochrane Systematic Reviews are generally considered on par with the highest level of evidence available. While none of these reviews specifically or exclusively focus on interventions for cancer treatment decisions, all the reviews do address cancer decision-making to a varying degree.

The CPRS program provides substantial evidence that putting these evidence-based interventions into practice by integrating them into the flow of a high volume cancer care clinic is feasible and effective. This evaluation is strengthened by a mixed-methods evaluation strategy that incorporates quantitative measures of effectiveness with qualitative data concerning logistics, workflow, and ways to improve service delivery.
III. Program Plan

Program Overview

The Patient Support Call Center (PSCC) program is a decision support service intended to help people newly diagnosed with early stage breast or prostate cancer become as informed and involved as they want to be while making treatment decisions with their doctors. While these patients are dealing with the shock, fear, and stress of their diagnosis, they also face a series of very difficult and often overwhelming treatment decisions. Our decision support intervention is ideally suited for patients with these particular cancers because no one treatment strategy has been proven to be clearly superior to the rest for all patients. As a result, a large number of acceptable treatment alternatives are available with a wide range of associated outcomes, and these patients face a highly preference-sensitive decision on how to proceed with the management of their disease.

Our program will utilize trained nursing students to administer 3 evidence-based decision support interventions including information gathering, question listing, and consultation recording/summarizing. The interventions will be delivered to program recipients over the telephone and a secure online portal will be used to share information. These interventions serve to better inform the recipient of their situation, prepare them to optimally address their information needs and personal preferences during the consultation, and improve their ability to recall information after the consultation.
**Program Context**

**Political Environment**

The political environment is conducive to the implementation of interventions that help inform and involve patients in the decision-making process regarding their cancer care, as these interventions are aligned with current local, state, and national priorities previously discussed. Legal and governmental policy organizations, academics, and governing bodies of the medical profession have generally supported the shift from paternalism to informed choice in medical decision making. Support is especially strong in situations where benefits are ambiguous and adverse outcomes are variable, as in decisions to undergo screening and treatment for cancer.\(^{36, 37}\)

In fact, in May 2007, the state of Washington formally endorsed the practice of SDM by passing legislation that encourages collaborative efforts to develop, certify, use, and evaluate tools and programs that help inform and involve the patient in medical discussions.\(^{38}\) Several more states are considering similar legislation that mandates pilot SDM projects, and federal legislation is under consideration in Congress which proposes similar experimental programs within Medicare.\(^{39}\)

Respected medical organizations including the IOM, American College of Physicians (ACP), the United States Preventative Services Task Force (USPSTF), the NCI, and the American Society of Clinical Oncology (ASCO), strongly endorse the practice of fully informing patients about all potential benefits and harms of all treatment options, and allowing the patient and physician to jointly choose the course of action that best suits the patients’ personal preferences.

While the theory of informed, SDM is broadly supported by clinicians, resistance to its practice on the individual practitioner level still exists. For numerous reasons, including time constraints, lack of familiarity and training, reimbursement disincentives, perceived patient
preferences and lack of motivation, physicians often fail to implement this method of decision making in practice.\textsuperscript{3, 40, 41} However, these barriers are not insurmountable, and effective, organized interventions that support and enhance physicians’ current practice are not likely to be controversial.

**Health System Factors**

The PSCC program will be introduced in the context of the existing framework of cancer management within a high volume oncology organization (HVOO), and will be framed as an intervention that improves the quality of the decision-making process by informing and involving the patient to a greater degree. As opposed to restructuring the current structure of cancer care delivery, this intervention will be an optional service which supplements the existing patient-provider relationship and enhances the patients’ ability to navigate through complicated cancer management decisions with their physician.

Within the HVOO system, participating physicians must be supportive of the PSCC program and encourage patients to take advantage of the interventions. PSCC trainees must be dedicated to connecting with eligible patients, and the trainees must champion the program by skillfully, professionally, and compassionately executing the interventions.

**Financial Resources**

Incorporating the PSCC program in to the existing infrastructure and resources of the HVOO will allow for substantial cost savings and efficiencies, especially in the realm of human resources and facility costs.
Financial compensation will be necessary for staff members involved in training the PSCC trainees. Funding will be necessary to cover the cost of training materials and intervention supplies, such as a conference calling and recording service, and software for referring eligible patients, sharing HIPAA-protected information, and record-keeping. Web-based portals exist (Microsoft Healthvault) for securely sharing medical records, question lists, consultation recordings and summaries among trainees, patients, and providers. Finally, marketing materials for recruiting trainees and raising physician and patient awareness of the program will necessary.

**Funding agency criteria**

Potential funding will come from philanthropic donations by social venture capitalists, Medicare and Medicaid funds, grants from other governmental agencies, CSC funds, and private insurance companies. Funding agencies must show a willingness to make a long term commitment to sustaining the CIN program.

**Technical/Administrative Feasibility**

Dr. Belkora and his staff have substantial experience in decision support service training through their work with the Breast Care Center at UCSF. Key to the administrative feasibility of this program is successfully creating business associate agreements (BAA) between the PSCC organization and both the trainee source and the HVOO to automate the referral process and seamlessly share information between PSCC trainees, patients, and providers.

The technical feasibility will hinge on the ease of use of the web-based medical information storage program and the referral system. PSCC trainees must be able to share the question lists, audio recordings, and consultations summaries with the patient and the physician.
in order for the interventions to be effective. The use of 3rd party “language lines” to translate medical encounters into different languages is widespread in hospitals, outpatient clinics, and community health centers, which suggests that audio recording of the treatment consultation through a telephone is technically feasible. Numerous companies offer web-based recording and digital storage of telephone conversations.

**Timeframe**

The timeframe for implementing the pilot phase of the PSCC program at 3 initial HVOO clinics is approximately 1 year. In the first 6 months, we must establish the PSCC organization as an independently functioning entity, identify a source of PSCC trainees, and create BAAs with the trainee source and the participating HVOO. Technical and administrative feasibility will be addressed by the end of the year. The upfront training of PSCC trainees will need to be complete within the year in order to begin offering the service to patients. Finally, the PSCC organization must identify and secure funding sources to allow the implementation of the pilot phase of the program.

**Stakeholders and Collaborators**

In order to create a sustainable, effective, widespread program for improving informed decision-making, a coalition of organizations and agencies with similar goals must be formed, and the intervention must benefit all members of the coalition to a certain extent.

First and foremost, physicians and patients must be willing to incorporate this model of decision-making into the traditional patient-provider dyad. In addition, participating organizations, such as the HVOO, must support the administration and promote the utilization of
the PSCC program. Finally, policymakers and medical organizations must come together to endorse this type of intervention, both by showing public support and providing financial assistance.

**Challenges**

We expect the PSCC program to face numerous challenges during its implementation, uptake, and maintenance. Securing sufficient, long term funding is certainly a significant concern. Convincing physicians to participate in an intervention that some may feel compromises their sense of autonomy and traditional way of practice may become problematic. Physicians may not initially be comfortable with an outside party recording the consultation via a conference call. However, these interventions have been generally well received by physicians in other settings, and an effort to help physicians understand the potential benefits to the patient will likely alleviate these concerns.

**Program Theory**

In planning the PSCC program, we utilize the ecological perspective of program theory, which emphasizes the interaction between, and interdependence of, factors from multiple levels of a health problem.\textsuperscript{42, 43} We consider factors that exert influence on the intrapersonal/individual, interpersonal, and community levels, and apply them to the PRECEDE-PROCEED planning model\textsuperscript{44} for identifying intervention strategies to address these factors.
Intrapersonal/Individual Level

Health-Belief Model (HBM) concepts, including perceived susceptibility, perceived severity, perceived benefits, cues to action, and self-efficacy, are employed to understand the individual characteristics that might influence a patient’s readiness to become informed and involved in the decision-making process. Planning the delivery of PSCC interventions must take into account how susceptible newly diagnosed cancer patients believe they are to making uninformed, uninvolved treatment decisions, and the perceived severity of the health outcomes resulting from these decisions. Participants must also believe that the interventions will increase their chance of becoming involved and informed, and be confident in their ability to effectively utilize the interventions offered by the PSCC program. As we plan this program, we must realize that patients need explicit cues to activate their participation in informed, SDM, and may face substantial psychological barriers to adopting the program’s intervention such as stress, anxiety, and emotional instability.

The target population of the PSCC program will likely be at various stages of acting as identified by the Precaution Adoption Process Model (PAPM). Many patients will be unaware that they have the option of being an active participant in their treatment decision (Stage 1), while others may be aware of this role but not engage in actions to become informed and involved due to lack of self-efficacy and/or psychological barriers (Stage 2). On the other hand, patients may have already decided that they want to take an active role in their treatment decision (Stage 5), and will benefit from the PSCC interventions by gaining the ability to act on this intention (Stage 6) and maintain their involvement in management decisions throughout the course of their illness (Stage 7). PSCC trainees need to be trained to recognize which stage each patient is in and tailor their interaction accordingly.
Interpersonal Level

The approach that newly-diagnosed cancer patients take towards making treatment decisions is influenced by social interactions with family members, friends, and health care providers, and environmental factors that include past experiences with illness, and their exposure to health information - concepts which are recognized by the Social-Cognitive Theory (SCT). A one-on-one interaction between the patient and the trainee will maximize patients’ behavioral capability and self-efficacy by arming them with the knowledge and skills necessary to actively participate in the decision-making process in a well-informed manner. By specifically addressing the patients’ questions, issues, and personal preferences and allowing the patient to become involved in the decision-making process, the consulting physician will not only further facilitate behavior capability and self-efficacy, but also fulfill the patients’ expectations of the PSCC program interventions and provide positive reinforcement of the patient’s participation in the interventions. A forum for patients to share and incorporate past experiences with illness, both their own and those of friends and family members, into the treatment discussion is essential to account for the interpersonal and environmental influences likely to affect how involved and informed a patient becomes in their treatment decision. The SCT asserts that patients observe the experience of others and model their expectations after these experiences. If a growing number of newly diagnosed cancer patients are able to become active participants in well-informed, well-considered treatment decisions through the PSCC program, other cancer patients who are facing management decisions will come to expect this type of decision-making experience.
Community Level

The “community” in the PSCC program context consist of patients, family and friends of patients, health care providers, and PSCC organization staff members who share the common interest of helping newly diagnosed cancer patients become as informed and involved in their treatment decision as they want.

The Organizational Change Stage Theory is used to conceptualize the stages that an organization must pass through in order to institute lasting change. The first stage is to define the problem. The HVOO organization must recognize that patients are not always able to become as informed and involved in their treatment decision as they want to be on their own. Both patients and cancer care providers must acknowledge that patients would benefit from being better informed about their illness, their treatment options, and possible outcomes prior to their consultation. They must also acknowledge that involving patients to a greater extent by soliciting their personal preferences is necessary to arrive at the best possible treatment decision. The affiliated providers move in to the second stage of change by adopting the PSCC program, allocating resources to begin implementation, and formulating policies and directives to guide implementation. The third stage of organizational change is full implementation of the program by providers and PSCC staff. Over the long term, the program is institutionalized as it becomes entrenched in the HVOO culture at sites all over the United States and emerges as a standard decision support practice provided by the organization and its affiliated providers and expected by the cancer patient community.

We utilize the Diffusion Theory of Innovations to plan how the uptake of the PSCC interventions will disseminate throughout the HVOO organization and the cancer community as a whole. The PSCC interventions necessarily offer a relative advantage to current practices of
informing and involving patients in treatment decisions. PSCC interventions will be simple enough to allow widespread understanding and utilization. PSCC trainees personalize the interventions in order to make them compatible with every individual in any population of newly diagnosed cancer patients. The “trialability” of the PSCC program is exemplified by plans to initially pilot the program at 3 HVOO sites in order to demonstrate the “observability” of intervention results before widespread adoption to other sites.

Goals and Objectives

Program Goal

The goal of the PSCC program is to help people with cancer be as informed and involved as they want to be while making treatment decisions with their doctors. Objectives were defined with the help of Dr. Jeffery Belkora, Ph.D. (telephone conversation, Feb. 5, 2010)

Program Objectives

We will use the “RE-AIM” format to organize program objectives into categories including program reach, effectiveness, adoption, implementation, and maintenance. We will use the “RE-AIM” format to organize program objectives into categories including program reach, effectiveness, adoption, implementation, and maintenance.

Reach:

- **Trainees**
  - By Aug. 2010, agreement will be made with trainee source to supply trainees for a period of at least 1 year at a time.
  - By Jan. 2011, PSCC staff (Dr. Jeff Belkora) will train 10 low-cost trainees to deliver PSCC interventions.

- **Referral pipeline**
By Jan. 2011, 3 HVOO-affiliated clinics will serve as referral centers to PSCC.

**Patients**
- By Jan. 2011, a total of at least 5 new patients per week will be enrolled in the PSCC program.

**Effectiveness:**
- By Aug. 2011, PSCC recipients will report an average pre-consultation Decision Self-Efficacy (DSE) score of at least 3 (on a validated 5 point scale).
- By Aug. 2011, PSCC recipients will report an average score of 2.5 or lower (out of 5) on the validated Decisional Conflict Scale (DCS).
- By Aug. 2011, PSCC recipients will report a satisfaction level with their consultation of at least 8, on a 10-point scale.

**Adoption:**
- **Patients**
  - By Jan. 2011, PSCC trainees will succeed in making contact with 50% of the potential recipients they attempt to call by phone.
  - By Jan. 2011, 50% of those patients reached by PSCC trainees will be enrolled in the PSCC program.
- **Trainees**
  - By Aug. 2011, 75% of PSCC trainees will be enrolling and delivering PSCC interventions to at least 1 patient per week on average.
  - By Jan. 2012, 100% of PSCC trainees will receive ongoing training and supervision during their first year.
By Jan. 2014, 90% of PSCC trainees will remain in this role for at least 1 year at a time.

Implementation:

- **Fidelity of Intervention**
  - By Jan. 2012, 90% of actual SCOPED notes (question listing intervention) created by trainees will be highly comparable to expert SCOPED notes created from audio recordings of question-listing sessions.
  - By Aug. 2011, 95% of completed question lists will be available to the patient online prior to the date of the consultation.
  - By Aug. 2011, 95% of audio recordings and consultations summaries will be available to patient online within 1 week of the consultation.

Maintenance:

- By Jan. 2012, a sustainable source of financing will be in place (ie. 3rd party payor)
- By Aug. 2013, 100% of BAA agreements with trainee sources & HVOO clinics will be renewed each year
- By Jan. 2012, the number of PSCC trainees and number of new patients enrolled each week will triple to 30 trainees and at least 15 new patients.

**Implementation Plan**

In order to successfully implement our program, we need to carefully plan how to structure our organization and deliver our services. This plan was developed with the help of Dr. Jeffery Belkora, Ph.D. (telephone conversation, Feb. 13, 2010).
Organizational Plan

The implementation of the organizational plan requires resources and inputs from numerous sources. [NEW ENTITY - (Name TBD)] will be founded as an independent organization and managed by a full time program director with the ability to establish working relationships with HVOO administration and cancer care providers, professional training organizations (nursing schools), and 3rd party payers (Medicare/Medicaid, insurance companies). The program director will oversee the implementation and delivery of the program, handle financial and legal issues, and ensure the sustainability and future growth of the program.

NEW ENTITY will enter into a Business Associate Agreement (BAA) with HVOO that permits the referral of patients to NEW ENTITY, allows sharing of protected health information (PHI), including medical records and contact information of patients with a new diagnosis of early prostate or breast cancer, and contains a contract for reimbursing NEW ENTITY for PSCC services. NEW ENTITY will also establish an agreement with the professional training organization (nursing school) which provides NEW ENTITY with a source of nursing students/service learners who will receive training in the delivery of PSCC decision-support interventions by Dr. Jeff Belkora of the University of California, San Francisco. In return, trainees will gain professional experience with one-on-one patient interactions, and learn valuable skills and techniques to assist patients in making informed, involved decision making. Nursing student trainees will work with NEW ENTITY on a volunteer basis or for course and/or practicum credit in agreement with their nursing school. Dr. Belkora and staff will administer both upfront and ongoing training for nurse trainees through online modules, videos, and case reports.
The BAA will facilitate the automatic referral of newly diagnosed prostate and breast cancer patients to NEW ENTITY. Patients who are contacted by trainees and agree to become recipients of PSCC program interventions will gain access to a secure, web-based portal for storing personal health information (e.g. Microsoft HealthVault). Through this portal, the trainee can obtain the patient’s medical records pertaining to their cancer diagnosis to tailor information gathering and connect the patient with information resources, as well as share outputs of the interventions with the patient (pre-consultation question list, audio recording and summary of the consultation).

**Service Utilization Plan**

Once the organizational plan has been implemented, the automatic referral system is in place, and the web-based medical information portal is functioning, the service utilization plan will come into effect.

In the initial stages of PSCC program implementation, we intend to utilize 3 HVOO-affiliated clinics to administer our intervention. From these 3 clinics, our target number of newly diagnosed prostate cancer or breast cancer patients that become PSCC program recipients is 5 per week. Assuming that the decision support interventions take a total of 6-8 hours per recipient and one trainee can provide the interventions to one recipient per week, a minimum of 5 trainees are initially needed. To account for potential problems synchronizing trainee and recipient schedules, we will employ twice the minimum number of necessary trainees to ensure that the program reaches 5 new recipients per week. Therefore, we will initially recruit and train 10 nursing student trainees for the pilot phase of our program.
HVOO providers and/or schedulers will identify appropriate when making appointments for treatment consultations for PSCC trainees to contact. Schedulers will provide potential recipients with information via email, pamphlet, and/or website about the PSCC program, and a handbook containing information regarding their disease, treatment options, and frequently asked questions. PSCC trainees will then contact these potential recipients via telephone to offer PSCC services. If the patient agrees to become a recipient, the PSCC will create an individual account on the web-based medical information portal (ie. Microsoft HealthVault). At the patient’s convenience, the trainee will administer a validated Decision Self-Efficacy (DSE) survey, provide the patient with additional resources for information pertaining to their specific condition, and administer the question-listing intervention using the SCOPED note format. The PSCC trainee will make the question list available on the web-based portal prior to the consultation. They will also email a copy to the patient and/or HVOO for use during the consultation.

PSCC trainees will discuss with the recipient how best to record the consultation. Using the speakerphone function on either the recipient’s personal cell phone or a NEW ENTITY-provided cell phone, the trainee will be dialed in to the consultation. This consultation will be recorded by a conference call recording service (AT&T, Conference-plus, Recordmycalls.com), converted into a digital file, and posted on the web-based portal for the patient to access. The trainee will use the recording to summarize the key points of the consultation, specifically addressing the questions and issues elicited in the pre-consultation question listing session.

PSCC trainees will make a follow up phone call to the recipient within one week to ensure that they successfully received all the intended interventions, administer a validated Decisional Conflict Scale (DCS) survey, and ascertain where the patient is in the decision-
making process. This marks the closure of one service unit cycle. At this point, the service cycle will either be permanently closed if the patient has made a treatment decision or reopened if the patient has another treatment consultation scheduled and would like to continue to receive the PSCC interventions.

**Sustainability**

In the long term, we envision the PSCC model becoming institutionalized as an integral service of the cancer care system. We hope that the cancer community will come to view this type of intervention as the standard of care for supporting decision-making, cancer patients will come to expect this type of service, and physicians will continue to effectively incorporate these decision-making strategies in the appropriate situations.

The challenge for our program beyond the implementation stage will be to maintain the support of cancer care organizations and their providers, expand the model to other arenas of cancer care, establish a stable source of PSCC trainees by integrating the provision of this service into the nursing curriculum, and implement a sustainable financing scheme.

By demonstrating to the participating HVOOs and providers that these patient-centered interventions improve the quality of decision-making in difficult, high-stakes situations, we hope to gain widespread acceptance within the HVOO network and the greater cancer care provider community. Supportive physicians and leaders in the field of cancer decision-making who endorse and champion the PSCC program interventions are critical for the sustainability and expansion of our program into a variety of cancer care provider organizations, both community-based and academic. The key to expansion of our program is PSCC’s model of a centralized, web-based referral and record maintenance system. As an increasing number and variety of
organizations begin to participate in the program, the increased demand will be easily met by increasing the capacity of our web-based systems. Growing personnel demands will simultaneously be met by increasing the number of trainees delivering the interventions.

Nurse educators and PSCC trainees must realize the benefit of gaining the experience of helping patients handle a difficult and stressful period in their life. Incorporating this type of learning experience into the nursing curriculum will contribute to establishing a continuous source of trainees for the PSCC program.

To secure sustainable financing, third-party payers must be convinced of the benefits covering this service for their beneficiaries. It will be necessary to enlist private insurance companies and public payers such as Medicare and Medicaid to help subsidize the cost of the PSCC program so that eventually, none of the extra cost of the decision-support services is borne by the recipient. As national, state, and local policies continue to shift their emphasis towards more patient-centered decision-making practices, the interventions provided by the PSCC program will become increasingly relevant to this emerging cancer care ideology. It is essential that our program capitalizes on this shift in order to gain support from financial, political, and medical institutions.

Throughout the first year of implementation, the program director will be charged with aligning patient demand with PSCC trainee supply to maximize the efficiency of human resources. While it is important to reach as many patients as possible, excessive investment in trainees is a waste of both financial resources and trainees’ time. As the program’s reach expands, the number of new trainees must grow appropriately to maintain efficiency.

Prudent analysis of program evaluation information is essential to assess the effectiveness, feasibility, and agreeability of certain aspects of service delivery. For example, it
may become clear that the benefits to the patients provided by the consultation recording intervention do not outweigh the logistical challenges and cost. Therefore, as the program progresses, certain aspects of service delivery may be modified, emphasized, and/or omitted. These strategies will ensure the sustainability of the PSCC program in order to make lasting improvements in the decision-making process of cancer patients.
## Logic Model

### Resources/Inputs:
- **Human**
  - Training staff (Dr. Belkora)
  - PSCC Trainees
  - HVOO Physicians
  - Program coordinator
  - Board of Directors or Professional Advisory Board
- **Collaborating partners**
  - Dr. Belkora (UCSF) – consultant/technical advisor
  - Trainee source
  - HVOO
- **Financial**
  - 3rd party payer (i.e. private insurance)
  - HVOO contributions
  - Philanthropic grants from social venture capitalists
  - Fee-for-service
- **Material**
  - Training materials
  - SCOPED note templates and software
  - Information sources/online resource kit (i.e. cancer.gov)
  - Conference call recording service
  - Web-based referral and contact management system
  - Secure web-based information storage and access portal
  - Oncology thought and practice leaders
    - Dr. Laura Esserman (UCSF)

### Activities:
- Train PSCC trainees
- Recruit HVOOs to participate in program
- Educate HVOO providers on PSCC program
- Providers/schedulers at HVOOs identify appropriate for enrollment, and inform them about program
- Trainees contact potential recipients via telephone and enroll in program
- Trainees administer pre-intervention decision self-efficacy (DSE) survey
- Trainees provide recipients with written and web-based materials with disease-specific information
- PSCC trainees help recipients create question list using the SCOPED note format prior to the consultation, which is made available to both recipient and physician online.
- Consultation is recorded using telephone and made available to trainee and patient online.
- Trainee uses recording to create document summarizing key points of consultation, answers to questions on question list, and other issues addressed in consultation, and makes available to recipient online.
- Trainee follows up with recipient about consultation, collects evaluation information, and administers decisional conflict scale (DCS) questionnaire.

### Outputs:
- Corps of nursing student trainees prepared to administer PSCC decision support services
- Stream of new patients from HVOOs referred to PSCC
- Targeted number of referred patients enroll in PSCC program
- Recipients receive information on their diagnosis from PSCC trainee
- Completed question available online prior to the date of the consultation.
- Audio recordings and summaries of consultation available online within 1 week of the consultation
- Post-consultation follow up interview with recipient

### Outcomes:
- PSCC recipients report an average DSE of over 3 (on validated 1-5 scale)
- PSCC recipients report an average DCS of under 2.5 after their medical visit (on validated 1-5 scale)
- PSCC recipients report an average satisfaction level of [8] or above (on validated 10 point scale)

### Impact:
- Newly diagnosed cancer patients are more informed about their diagnosis and treatment options at the time of their treatment consultation.
- Newly diagnosed cancer patients are more involved in their treatment decision consultation.
- Improved patient-provider communication during consultation.
- Greater alignment between patient preferences and treatment decision.
- Increased patient satisfaction with consultation and treatment decision.
- Increasing number of providers and HVOO clinics adopting PSCC program
- Physicians at HVOO incorporate PSCC interventions into daily practice
- Policy changes supporting use of decision-support services
IV. Evaluation Plan

Introduction

Program Overview & Rationale for Evaluation

While progress in modern medicine and advancements in the treatment of cancer have certainly led to improvements in disease survival and quality of life, the multitude of treatment options for diseases such as early breast and prostate cancer has inevitably become overwhelming for many patients as they struggle to weight the benefits and possible harms of these different options. As a result, many patients with a new diagnosis of early breast or prostate cancer are not able to become informed, involved participants in their treatment decisions and subsequently are not able to effectively align their course management with personal preferences. To address this public health issue, the PSCC will be implemented to provide patients at a HVOO with evidence-based interventions that improve the quality of decision-making. These interventions include information gathering, question listing, and consultation recording/summarizing.

While these interventions are morally justified, grounded in a strong evidence base, and have been shown to be effective, feasible, and acceptable to cancer patients in a real clinical setting, our program requires evaluation for several reasons. First, our program delivery strategy, which utilizes a centralized call center model, is a novel approach to administering these interventions. While successfully delivered in other settings, the complex fiscal, socioeconomic, demographic, interpersonal, and interorganizational context of our program provides a wealth of challenges and potential obstacles. Evaluation will help us determine if our program is succeeding in overcoming these contextual challenges. Second, since this method of service delivery is new and untested, a systematic evaluation will give us the opportunity for
ongoing quality improvement of the design and management of many aspects of program implementation and activities. Third, evaluation will allow us to monitor our progress towards program goals and justify the continued support and utilization of our program to our funders, stakeholders, staff members, and participants. If the program is not only feasible and acceptable to all parties involved, but also successful in achieving our goal of improved quality of decision-making for patients, it will increase the potential for expansion of the program and widespread dissemination of these methods.\textsuperscript{46}

**Evaluator Role**

The role of the PSCC evaluator will be to engage stakeholders to actively participate in the evaluation, and manage all evaluation activities, which include planning and budgeting for the evaluation, developing evaluation objectives, addressing data collection issues, reporting findings, and working with stakeholders and collaborating evaluators.\textsuperscript{46, 47} The ideal evaluation strategy is to form a team that is headed by an internal evaluator and supplemented by an external evaluator and stakeholder representation.\textsuperscript{47} The internal evaluator brings an invested, participatory approach to the team while the external evaluator serves to maintain a professional distance from the program and program staff and provide fresh perspectives and insights to the evaluation. Contributions from stakeholders are necessary to ensure the evaluation addresses the information that these parties are most interested in.

It is essential that the lead evaluator a strong foundation in the program theories that directed the development of our program plan. He or she must also possess a firm understanding of the service delivery strategy and specific activities. The most important individual characteristics of a successful evaluator are:\textsuperscript{47}
- Strong communication skills with all levels of personnel
- Leadership, management, and organizational ability
- Ability to remain flexible and problem solve as the evaluation progresses
- Previous evaluation experience
- Ability to work well with a wide variety of stakeholders, including training staff, nursing school administrators, trainees, HVOOs and their providers, and funding agencies
- Understanding of the goals of evaluation and how it will be used
- Ability to be objective, honest, and thorough in collection of data and reporting of findings
- Familiarity in both qualitative and quantitative data collection and reporting
- Technical ability to collect, maintain, and interpret process measures through automated web-based applications.

**Stakeholder Input**

Key stakeholders of our program are those that increase the credibility of our evaluation, implement the key activities of the evaluation, advocate for changes to institutionalize the evaluation findings, and fund/authorize continuation and expansion of the program. These include the HVOO and its cancer care providers, the nursing schools that provide trainees, the trainees who deliver the intervention, the training staff, funding agencies, potential 3\textsuperscript{rd} party payers, and program recipients. Involving those stakeholders that are directly involved in delivering and receiving program services helps identify areas for improvement in the activities leading to program outputs. Engaging those stakeholders who will use evaluation information to determine whether they will continue to fund, support, and participate in the program is
necessary to identify the information these stakeholders deem necessary to make these decisions. It will be beneficial to have stakeholder representatives on the evaluation team to help define questions and outline data collection and evaluation methods.

Questions that will be asked of stakeholders include: What about this program is important to you? What would you like this program to accomplish? What questions do you see as critical to the evaluation? How much progress do you expect this program to make? How will you use the results of this evaluation? What resources are you willing to contribute to the evaluation?

Conversely, stakeholders might be expected to ask: What is the duration of this program? What resources will I be expected to contribute to the evaluation? How will my input be incorporated into the evaluation? How will I be informed of evaluation results?

**Challenges**

Constructing an evaluation that caters to the needs of all stakeholders is no simple task and we expect to encounter numerous challenges: Justifying that each of the three interventions is necessary to achieve our goal of informing and involving patients; proving that our interventions are the cause of the changes in outcome measures, rather than other factors; engaging busy stakeholders (physicians) to participate in evaluation; measuring and reporting less-quantifiable impact objectives using Interpretivism/Constructivism and Theory-based evaluation methods; and convincing funders that progress towards the desired impact may not be initially self-evident, but that a long term commitment to the evaluation is necessary.
Evaluation Study Design & Methods

Design

While designing our evaluation plan, we took into account the need to evaluate both implementation/process measures, as well as effectiveness/outcome measures. Our novel service delivery model will require ongoing process evaluation to determine whether or not our program has been implemented as planned – also known as “implementation fidelity”. We will need continuous information regarding what activities are actually taking place, what is the reach of our program, and whether sufficient inputs been allocated and mobilized.46 If actual performance falls short of planned performance, our evaluation must serve to explain the differences and suggest ways to make improvements.

The decision-support interventions included in our program have each been extensively researched and found to be effectiveness in improving the quality of the decision-making process.20,30,32 In addition, the integration of these decision-support services into the clinical setting has been previously shown to be effective and agreeable to participants, staff members, and physicians.6 Therefore, we feel that while determining a causal relationship between our intervention and patient-centered outcomes (decision self-efficacy, decisional conflict, and satisfaction with the consultation) is certainly ideal, it is not strictly necessary to justify the benefits of our program. Rather, acceptance of the prolific evidence base and moral foundation on which our program is grounded is essential. Consequently, we chose to focus of our evaluation more heavily on implementation, adoption, and acceptance rather than proving causality.

Given these considerations and the nature of our program, we will utilize a one group, pre-test/post-test evaluation design for the outcome/effectiveness measures of interest.
Collecting and analyzing data only from program participants is the most practical and efficient use of evaluator time and resources. In addition, soliciting evaluation information from newly diagnosed cancer patients is already a delicate issue and would be excessively intrusive, insensitive, and unjustified in those patients who have not agreed to participate in our program.

For the implementation/process evaluation, the pre-experimental design is the least complicated and least expensive strategy that is still sufficient for outcome documentation. Data will be collected continuously as the program is implemented, and participants are enrolled and receive the interventions. The pre-experimental design allows us to compare data at various points in time to the pre-stated objective targets.  

**Methods**

Appropriate evaluation methods are necessary to meaningfully answer our evaluation questions. The most effective way to address our wide variety of evaluation questions is to combine quantitative data with qualitative analysis that not only answers our pre-stated questions, but also provides us with information for ongoing modification and improvement of our program.

Quantitative data will be collected from several sources. Successful achievement of our implementation objectives will be evaluated using training records, the business associates agreements (BAAs), and online enrollment records. Reviewing our online record system where participants’ medical records, questions lists, and audio recordings and consultations are stored will allow us to evaluate the extent to which our reach, adoption, implementation and maintenance objective targets are met. To evaluate our effectiveness objectives, we will collect
data on decision self-efficacy (DSE) and decisional conflict (DSC) according to widely used, validated methods.\textsuperscript{49}

Qualitative measures will be utilized in our program evaluation in order to learn about the strengths and weaknesses of the implementation and execution of our program. The extent to which our program is adopted and accepted by potential participants, program staff, cancer care providers, and 3\textsuperscript{rd} party payers is essential to our evaluation, and qualitative analysis is the most useful way to determine what is working and what needs to be improved to guide the future direction of our program. The main strategy for collecting this information will be through focus groups and open-ended interviews. Depending on what evaluation question is being asked, HVOO clinic administrators, cancer care providers, program staff, and participants will be involved in the focus groups and open-ended interviews.

Focus groups have the advantage of being cost and time efficient as they only require a small number of evaluator man-power to collect information from a large number of people. They have the advantage of promoting collaboration, brainstorming, and discussion between various stakeholders who have differing points of view. Evaluators may therefore be more successful in collecting information leading to improvements which benefit a wide range of stakeholders. On the other hand, focus groups may not be appropriate for certain outcome measures that involved revealing personal information to the group. Focus groups, for the purpose of our evaluation, are most useful for process and implementation monitoring.\textsuperscript{48}

Individual open-ended interviews are less efficient, but often have a high response rate. Our interviews will be conducted over the phone to program participants, who are likely to be personally invested in the program interventions and will hopefully be willing to contribute their perspective and reflect on their experience to help improve the program. The number of
individual, in-depth, open-ended interviews that can be conducted by our evaluators will be limited by time and money constraints. Therefore, a convenience sample of patients will be taken among those who received the interventions as planned. Additionally, it will be informative to interview those participants who did not successfully receive all planned interventions and investigate the shortcomings in our implementation that prevented full service delivery and complete fidelity to the program plan.

**Dissemination Plan**

While our evaluation period does not have a distinct termination point, periodic reporting of evaluation results is necessary to monitor the progress of our program and reassure our stakeholders and funding agencies that the program is being carried out as intended. After the first year of implementation, a formal written report will be submitted to key stakeholders, including the oncology clinic administrators, board members, and physicians, nursing school administrators, and funding agencies. This report may include an executive summary outlining the structure and organization of our program, the background, rationale, and context of our program, utilization data, and key quantitative and qualitative outcomes.

Stakeholders will also be interested in ongoing efficiency and quality improvement efforts. Biannual review of evaluation data, especially focus groups and in-depth interviews, will be compiled in order to guide these improvement efforts as the program expands its reach. The ongoing quality improvements must be shared with program staff, nursing school administrators, referring physicians, and the oncology group administrators to ensure that modifications made to program organization and service delivery are understood and adopted by all participants.

Importantly, evaluation results must be shared with external groups that promote the process of informed, involved decision-making in cancer care. We will report our methods and
patient-centered benefits of our program, using both quantitative and qualitative results, to national health organizations (National Cancer Institute, American Cancer Society, Institute of Medicine), policy advocacy groups, and other high volume oncology groups in both private and academic settings. It will be prudent to draft manuscripts for publication in a wide range of journals, which may include, *Patient Education and Counseling, Medical Decision Making, Journal of Clinical Oncology, Annals of Oncology, American Journal of Preventive Medicine,* and *Annals of Internal Medicine,* among others. We will seek out opportunities to present the key findings of our program at oncology meetings, forums on informed decision-making, and professional training organizations such as medical schools and nursing schools, in order to familiarize a wide range of both medical and non-medical personnel with the underlying concepts and program methods. These activities are essential to further progress towards a more patient-centered approach to treatment decision-making in cancer care which allows patients to become as informed and involved as they want to be.

**Evaluation Questions:**

**Objective 1 (Reach):** By Jan. 2011, PSCC staff (Dr. Jeff Belkora) will train 10 low-cost Nursing student trainees to deliver question-listing support services

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Jan. 2011, are 10 low-cost Nursing student trainees actually trained to deliver question-listing support services by PSCC staff (Dr. Jeff Belkora)</td>
<td>Nursing school educators/administrators, training staff</td>
<td>Review training logs</td>
</tr>
<tr>
<td>What were the barriers that made training nursing students difficult?</td>
<td>Nursing student trainees, training staff, nursing school educators/administrators</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>What aspects of the training process were effective and agreeable?</td>
<td>Nursing student trainees, training staff, nursing school educators/administrators</td>
<td>Focus groups, open-ended interviews</td>
</tr>
</tbody>
</table>
How can the training process be improved?
Nursing student trainees, training staff, nursing school educators/administrators
Focus groups, open-ended interviews

Did trainees gain adequate knowledge from training process?
Nursing student trainees
Pre/post-tests of decision-making process knowledge

**Objective 2 (Reach):** By Jan. 2011, 3 HVOO-affiliated clinics will serve as referral centers to PSCC program

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
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</thead>
<tbody>
<tr>
<td>By Jan. 2011, are 3 HVOO-affiliated clinics serving as referral centers to PSCC program?</td>
<td>Program director, HVOO clinic administrators</td>
<td>Review Business Associates Agreements (BAA)</td>
</tr>
<tr>
<td>How were clinics successfully recruited to participate?</td>
<td>Program director, HVOO clinic administrators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>What barriers prevented clinics from participating?</td>
<td>Program director, HVOO clinic administrators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>How could barriers to participation be overcome?</td>
<td>HVOO clinic administrators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>Where the interests of the HVOO-affiliated clinics addressed when forming the partnership with PSCC?</td>
<td>HCOV clinic administrators</td>
<td>Open-ended interviews</td>
</tr>
</tbody>
</table>

**Objective 3 (Reach):** By Jan. 2011, a total of at least 5 new patients per week will be enrolled in the PSCC program.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Jan. 2011, are a total of at least 5 new patients enrolling in the PSCC program per week?</td>
<td>Program director</td>
<td>Review online enrollment records</td>
</tr>
<tr>
<td>What factors prevent patients from enrolling in the program?</td>
<td>Nursing student trainees, eligible patients who did not enroll</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>What aspects of the enrollment process are successful?</td>
<td>Nursing student trainees, participants</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>How can enrollment process be improved?</td>
<td>Nursing student trainees, program director, HVOO administrators</td>
<td>Open-ended interviews</td>
</tr>
</tbody>
</table>

**Objective 4 (Effectiveness):** By Aug. 2011, PSCC recipients will report an average pre-consultation Decision Self-Efficacy (DSE) score of at least 3 (on a validated 5 point scale), an average score of 2.5 or lower (out of 5) on the validated Decisional Conflict Scale (DCS) after the consultation, and a satisfaction level with their consultation of at least 8 (out of 10).*
By Aug. 2011, will PSCC recipients report an average pre-consultation Decision Self-Efficacy (DSE) score of at least 3 (on a validated 5 point scale), an average score of 2.5 or lower (out of 5) on the validated Decisional Conflict Scale (DCS) after the consultation, a satisfaction level with their consultation of at least 8, on a 10-point scale.

Are there any logistical problems administering pre- and post-consultation interviews and surveys to participants?

Do patients have any personal objections or emotional barriers to answering the interview/survey questions? If so, what are they?

How can the pre- and post-consultation interview/survey process be improved?

*Individual effectiveness objectives are combined into a single objective since evaluation questions, participants, and evaluation methods are the same for each individual objective*

**Objective 5 (Adoption):** By Jan. 2011, 50% of those patients reached by PSCC Nursing student trainees will be enrolled in the PSCC program

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>By Jan. 2011, are 50% of those patients reached by PSCC Nursing student trainees enrolled in the PSCC program</td>
<td>Nursing student trainees</td>
<td>Contact and enrollment logs</td>
</tr>
<tr>
<td>What prevents patients from enrolling in the program?</td>
<td>Nursing student trainees, non-participating patients</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>What aspects of the enrollment process are successful?</td>
<td>Nursing student trainees, participants</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>How can enrollment process be improved to increase rate of enrollment?</td>
<td>Nursing student trainees, participants</td>
<td>Focus groups, open-ended interviews</td>
</tr>
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</table>

**Objective 6 (Adoption):** By Aug. 2011, 75% of PSCC Nursing student trainees will be enrolling and delivering PSCC interventions to at least 1 patient per week on average.

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<tr>
<th>Evaluation Questions</th>
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<tbody>
<tr>
<td>By Aug. 2011, are at least 75% of PSCC Nursing student trainees enrolling and delivering PSCC interventions to average of at least 1 patient per week?</td>
<td>Program director</td>
<td>Enrollment and output logs</td>
</tr>
</tbody>
</table>
Is enrolling 1 patient per week an appropriate work load? | Nursing student trainees, program director | Focus groups, open-ended interviews
---|---|---
What barriers exist to enrolling at least 1 patient per week? | Nursing student trainees, program director | Focus groups, open-ended interviews
How can barriers to enrollment be overcome so that each trainee can enroll at least 1 patient per week? | Nursing student trainees, program director | Focus groups, open-ended interviews

**Objective 7 (Adoption):** By Jan. 2014, 90% of PSCC Nursing student trainees will remain in this role for at least 1 year at a time.

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<tr>
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<th>Evaluation Methods</th>
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</thead>
<tbody>
<tr>
<td>By Jan. 2014, are 90% of PSCC Nursing student trainees remaining in this role for at least 1 year at a time?</td>
<td>Program director</td>
<td>Review training and participation logs</td>
</tr>
<tr>
<td>Why are Nursing student trainees unable to remain in this role for 1 year?</td>
<td>Nursing student trainees, former nursing student trainees, nursing school educators/administrators</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>What support services could be offered to help Nursing student trainees remain in this role for 1 year?</td>
<td>Nursing student trainees, program director, nursing school educators/administrators</td>
<td>Focus groups, open-ended interviews</td>
</tr>
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**Objective 8 (Implementation):** By Jan. 2012, 90% of actual SCOPED notes created by trainees will be highly comparable to expert SCOPED notes created from audio recordings of question-listing sessions.

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</thead>
<tbody>
<tr>
<td>By Jan. 2012, are 90% of actual SCOPED notes created by trainees highly comparable to expert SCOPED notes created from audio recordings of question-listing sessions?</td>
<td>Training staff</td>
<td>Review of expert SCOPED notes and trainee-created SCOPED notes</td>
</tr>
<tr>
<td>How do trainee-created SCOPED notes fall short of expert SCOPED notes?</td>
<td>Training staff</td>
<td>Review of expert SCOPED notes and trainee-created SCOPED notes</td>
</tr>
<tr>
<td>How can trainee-created SCOPED notes be improved to more closely resemble expert SCOPED notes? Can systematic deficiencies be identified and corrected by changes in training program?</td>
<td>Training staff, program director</td>
<td>Focus groups</td>
</tr>
</tbody>
</table>

**Objective 9 (Implementation):** By Aug. 2011, 95% of completed question lists will be available to the patient online prior to the date of the consultation and 95% of audio recordings...
and consultations summaries will be available to patient online within 1 week of the consultation.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Aug. 2011, are 95% of completed question lists available to the patient online prior to the date of the consultation and are 95% of audio recordings and consultations summaries available to patient online within 1 week of the consultation?</td>
<td>Program director</td>
<td>Review participant files in online portal</td>
</tr>
<tr>
<td>What barriers exist to making question lists and audio recording/summaries available on time?</td>
<td>Nursing student trainees, program director</td>
<td>Focus groups, open-ended interviews</td>
</tr>
<tr>
<td>What improvements can be made to make it easier for question lists and audio recordings/summaries to be made available online in time?</td>
<td>Nursing student trainees, program director</td>
<td>Focus groups, open-ended interviews</td>
</tr>
</tbody>
</table>

**Objective 10 (Maintenace):** By Aug. 2013, 100% of BAA agreements with trainee sources & HVOO clinics will be renewed each year.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
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<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Aug. 2013, were 100% of BAA agreements with trainee sources &amp; HVOO clinics renewed each year?</td>
<td>Program director</td>
<td>Review BAA contracts</td>
</tr>
<tr>
<td>What reasons did trainee sources (nursing schools) not renew the BAA and discontinue participating in the PSCC program?</td>
<td>Nursing school administrators, program director</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>What reasons did HVOO clinics not renew the BAA and discontinue participating in the PSCC program?</td>
<td>HVOO administrators, program director</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>How can PSCC program and BAAs be modified to ensure yearly renewal by all participating entities?</td>
<td>Nursing school administrators, HVOO administrators, program director</td>
<td>Focus groups, open-ended interviews</td>
</tr>
</tbody>
</table>

**Objective 11 (Maintenance):** By Jan. 2013, the number of PSCC trainees and number of new patients enrolled each week will triple to 30 trainees and at least 15 new patients.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
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<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Jan. 2013, has the number of PSCC trainees and number of new patients enrolled each week tripled to 30 trainees and at least 15 new patients?</td>
<td>Program director</td>
<td>Review training logs, review enrollment logs</td>
</tr>
</tbody>
</table>
What aspects of the program have allowed successful expansion in the number of trainees?

| Program director, nursing school administrators | Longitudinal surveys, open-ended interviews |

What aspects of the program have allowed successful expansion in the number of patients referred?

| Program director, HVOO clinic administrators | Longitudinal surveys, open-ended interviews |

What factors have prevented the program from expanding? How can these factors be overcome?

| Program director, nursing school administrators, HVOO clinic administrators | Longitudinal surveys, open-ended interviews |

V. Discussion

The management of cancer and chronic disease requires patients and physicians to make complex, difficult, value-based decisions about the best strategy for treatment. For disease such as early prostate and breast cancer, numerous treatment options exist with varying potential harms and benefits. When no one treatment option is superior, the best treatment decision for each patient depends on their personal preferences.

While SDM has recently emerged as the recommended paradigm for addressing preference-sensitive decisions in disease management, efforts to implement this strategy in practice have fallen short. Numerous barriers inhibit physicians from soliciting patient preferences, and patients are often not up to the challenge of becoming informed and involved in their treatment decision.

However, several intervention strategies which promote SDM have been thoroughly researched, including information gathering/decision aids, pre-consultation question listing, and consultation summarizing/recording. Individually, these interventions have been shown to improve certain aspects of the decision-making process, and the integration of all three of these interventions into the flow of a high volume breast cancer center has been successful.
The goal of this Masters Paper is to plan a program that utilizes evidence-based and morally grounded interventions to improve the quality of treatment decisions made by newly diagnosed breast and prostate cancer patients and their physicians by empowering patients to become as informed and involved as they want to be in their treatment decision, and increasing physician awareness of the personal preferences of their patients.

The long term goal for this program is to further encourage the culture of SDM in cancer care by disseminating these concepts and strategies to the wider cancer care community. Our program utilizes an innovative service delivery strategy, which involves delivery of the decision-support interventions by trainees via telephone. This model has both advantages and disadvantages. While it lacks the benefits of face-to-face personal contact, this strategy facilitates the efficient increase in program capacity in order to rapidly expand the reach of the program, both within the HVOO and in other health care settings.

On a personal level, I find the concepts and strategies laid forth by this program plan to be essential for high quality care. In my future career as a Urologic Oncologist, I foresee a large part of my daily practice revolving around helping patients make the treatment decision that best suits their individual goals and preferences. I believe that utilizing a decision-support program such as the one described in this paper will greatly enhance the experience of the patient, and ensure that as a physician, I am adequately soliciting patient preferences and that our ultimate treatment strategy aligns with those preferences. Much is made in public health about overdiagnosis and overtreatment, particularly in cancer care. While the debate about overdiagnosis of breast and prostate cancer by PSA screening and mammography, respectively, is likely to continue for some time, I believe that the most effective way to address the problem of overtreatment in cancer care is to work to better inform and involve the patient in the
treatment decision. This program is only one strategy for improving the quality of decision-making in cancer care and much work still needs to be done to ensure that all patients are afforded the opportunity to become as informed and involved as they want to be in the management of their disease.

VI. Acknowledgements

I want to thank Dr. Diane Calleson, Pamela Dickens, and the rest of the Public Health Leadership faculty at the University of North Carolina, Chapel Hill, School of Public Health for their help and support throughout this year. I also want to give a special thanks to Dr. Jeff Belkora for the vision and inspiration for this program plan, as well as his guidance and mentoring throughout the development of this project.

VII. References


