Program Plan and Evaluation for the Skin Cancer Prevention Initiative: A Collaborative Skin Cancer Prevention Program for Transplant Recipients at the University of North Carolina.

By

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I. INTRODUCTION

In recent years, long-term survival of solid organ transplant recipients (SOTRs) has improved significantly\(^1\text{-}^2\). In 2008, roughly 223,000 organ transplant recipients were alive in the United States. Due to the effects of long-term immunosuppressive therapy required to prevent transplant rejection, SOTRs are at extremely elevated risk of developing non-melanoma skin cancer (NMSC), which includes squamous cell carcinoma (SCC) and basal cell carcinoma (BCC).

Cutaneous SCC is the most common cancer to develop after transplant, with an incidence 65-250 fold higher than sex- and age-matched controls\(^3\text{-}^6\). SOTRs also have a 10-fold increased risk of developing BCC\(^3\text{-}^6\). The risk of melanoma in SOTRs is unclear. Some studies have found a 2-8 times greater risk of developing melanoma compared to the general population\(^6\text{-}^7\) and other studies have found no increased risk\(^8\). The median time to development of NMSC in transplant patients is typically 4-9 years\(^3\text{-}^9,^10\).

The high prevalence of skin cancer among SOTRs is not the only challenge. SCCs that develop in transplant patients are more likely to be exceptionally invasive than those in the general population\(^11\text{-}^13\). They are also more likely to metastasize, with approximately 7% of cutaneous SCCs in transplant patients becoming metastatic\(^14\). Additionally, SOTRs are at risk of developing field cancerization, a condition in which a region of skin shows multiple precancerous or cancerous changes\(^15\).

Among SOTRs, some patients are at the highest risk for developing skin cancers. Those who have had a previous NMSC are 49 times more likely to develop a subsequent NMSC compared to patients who have never had one\(^16\). Patients with fair complexions and blue eyes are at higher risk of developing NMSC than patients with darker complexions, and risk increases...
with age\textsuperscript{17}. Duration, type, and intensity of immunosuppression significantly affect skin cancer risk and may not be modifiable\textsuperscript{18}.

Sun exposure is a particularly important risk factor because of its modifiable nature. Cumulative lifetime sun exposure, sun exposure before transplantation\textsuperscript{17,19}, and long-lasting recreational sun exposure have been strongly associated with development of NMSC in SOTRs\textsuperscript{20}. In a 24-month prospective matched control study, regular use of sunscreens and sun-protective clothing appeared to be effective in reducing the number of new NMSCs and actinic keratoses, SCC precursor lesions\textsuperscript{21}. While this is extremely promising, in order for such strategies to be effective in preventing skin cancers, transplant recipients must recognize the need for sun-protective behaviors and understand how to engage in them.

Multiple surveys have identified deficits in transplant patients’ knowledge of skin cancer risk and prevention. In a survey of 122 organ transplant patients in Hershey, PA, 50% said they did not know immunosuppressant medications put them at elevated risk of skin problems and 41% did not recall learning about the increased risk of skin cancer after transplantation\textsuperscript{22}. Another survey of 200 transplant recipients in New York found that only 22% of respondents thought they were at higher risk for developing skin cancer than the general public\textsuperscript{23}.

Even if patients know about their elevated risk of skin cancer and recognize what protective behaviors can be effective in reducing their risk, other factors such as motivation and attitudes towards sun-protective behaviors may be important in determining whether they engage in those protective behaviors. In the same survey of 200 transplant recipients in New York, 81% of respondents reported they believed people look “healthier” with a tan, compared to 64% of the US public\textsuperscript{23}.
Regular skin examination is another strategy that may prevent skin cancer morbidity and mortality in transplant patients. By allowing early detection and removal of cancers, skin examinations may help reduce the risk of metastasis or the likelihood of disfigurement from invasive treatments. The American Academy of Dermatology recommends that all transplant patients undergo regular skin screening examinations including skin self-examinations and at least yearly total body skin examinations by a healthcare provider\(^\text{24}\). SOTRs with extensive sun damage, precancerous lesions, or skin cancer should be seen more frequently\(^\text{15}\).

In order to improve skin cancer prevention and promote early detection of skin cancers among transplant patients at the University of North Carolina, I conducted a series of interviews with dermatologists and transplant clinic staff to identify areas for potential improvement. Through these interviews, I identified several areas of need including: a streamlined dermatology referral process, clear guidelines about what education SOTRs should receive, additional written information about skin cancer risk for patients, and a risk assessment tool to quickly determine which patients are at the highest risk of developing skin cancer.

Based on the results of this formative research, the Skin Cancer Prevention Initiative (SCPI) program and evaluation plan was developed with the goal of improving skin cancer prevention and management for UNC’s transplant patients through collaborations between the dermatology department and various transplant clinics. Key components of the program include addressing needs identified through formative research and incorporating educational interventions that have been successful in other similar programs.

The first section of this paper is a systematic review of the literature to identify existing skin cancer prevention programs with components that could be feasibly implemented within the SCPI. Review of these programs helped to identify which strategies appeared most effective at
promoting sun protective behaviors. The second section of this paper consists of the SCPI program plan. The program plan addresses the context, relevant theories, and goals of the program as well as a logic model, implementation plan, and budget. The third section is the evaluation plan, which includes information about how and why the program should be assessed. The paper concludes with a discussion of program significance and future directions.
II. SYSTEMATIC REVIEW

Introduction

In order to build on the experiences of previous programs, I used a systematic search strategy to identify published programs with similar characteristics to the Skin Cancer Prevention Initiative. I then summarized and analyzed programs that met inclusion criteria (i.e. were highly relevant to this project) to determine what aspects of those programs would be best for inclusion or exclusion into the SCPI.

Methods

The primary research question of this search strategy was: What programs geared toward promoting sun protective behaviors or skin self-examination have been previously implemented and evaluated? After conducting a preliminary literature search to identify key terms to use, I searched MEDLINE using the following search terms: "Health education"[mesh] AND ("skin neoplasms"[mesh] OR sunscreen OR sun[title]) AND (intervention OR program OR evaluation). The search was limited to English language articles and articles published from the beginning of MEDLINE to March 1, 2013. Reviews and letters to the editor were excluded because the purpose was to assess original publications about relevant programs. One-hundred and fifteen articles were initially generated. I also searched reference lists and abstracts of relevant articles to identify additional relevant material.

For a program to be deemed sufficiently similar to SCPI and relevant for this review, the following were required (a) target population must be adults, preferably middle-aged or older and including both men and women (b) primary goal is increasing use of sun-protective behaviors with an ultimate goal of reducing individuals’ risk of skin cancer, (c) intervention could be feasibly implemented in a health care-based setting, (d) program evaluation results were
available, and (e) the primary purpose of the article must be to describe the program and its evaluation. Articles about skin self-examination (SSE) promotion were excluded if they focused primarily on melanoma but not other types of skin cancer. The target population was not limited to transplant patients since skin prevention education programs effective in other adults are likely to also be effective in transplant recipients. After conducting the search strategy and applying the inclusion and exclusion criteria, I identified the six most relevant programs.

**Summary of Programs**

*Project SUNWISE*

Project SUNWISE is a program piloted by the United States Postal Service in Southern California with the goal of promoting regular occupational use of wide brim hats and sunscreen with a SPF of 15 or higher among postal workers. Postal workers are at high risk for skin cancer, as evidenced by the demographics of those participating in the study. On average, they reported spending nearly 4 hours per day in the sun, and roughly 50% had had a previous skin cancer.

Project SUNWISE was grounded in several theories. The ecological model that emphasizes the roles of environment and policy was a primary component. Key constructs from operant models emphasizing reinforcement and environmental prompts for changing behavior were used. Additionally, Social Learning Theory’s constructs of modeling, social influence, reciprocal determinism, and self-efficacy were also used to design the program.

Particular components of the program included providing postal workers with free wide brim hats, stocking locker rooms with large pump bottles of SPF 30 sunscreen, providing letter carriers with small bottles to carry sunscreen with them, and delivering six short educational messages (to create opportunities for modeling and social influence) about sun protective
behaviors over the course of the two year intervention. Project SUNWISE staff also distributed water bottles, key chains, etc. with sun safety messages. Sun safety questions with answers were posted in break rooms. Incentives valued at less than $10 each were also used to promote participation.

The educational messages were five to ten minute long presentations involving large colorful flip charts. They included information about the amount of UV radiation carriers were exposed to and the role of UV radiation in skin cancer development. They also included a case report of a letter carrier with a precancerous growth removed, information about protective strategies, and specific details about the hats and sunscreen being made available. Themes of subsequent presentations included: 1) importance of sun safety, even in winter, 2) sun safety for eyes, 3) sun safety tips for loved ones, 4) sun safety relevance for carriers of all ethnicities, and 4) a final recap and encouragement to continue practicing sun protective behaviors.

In order to assess the efficacy of the program, a delayed intervention group of post offices served as a control. Seventy postal stations in three different regions of Southern California ultimately participated, either as an initial program site or a delayed intervention site. Control stations participated in evaluations only for the first two years of the program, until 2 year evaluations were completed. They then received all components of the program over the subsequent year.

Data were collected prior to the start of the program, at 3 months, at 1 year, and at 2 years. At the first evaluation, letter carriers were not aware of their station’s study group assignment. Topics measured in the surveys included how often in the past 5 workdays each person used a sunscreen with SPF 15 or higher and wide brim hats. Research assistants directly observed a portion of participants prior to each survey to record clothing worn during mail
delivery. Sunscreen-wearing was also validated by correlating the quantity of sunscreen removed from the communal pump bottles at each station with the percentage of men and women who reported they “always used sunscreen in past 5 workdays”. Their methods of analyzing the data were fairly robust, and analyses were adjusted for the baseline level of each corresponding outcome variable.

Self-reported sunscreen and hat use were consistent with the results of direct observations and the measurement of sunscreen removed from the stations. At 2 years, intervention group participants were twice as likely to report always using sunscreen and 2.88 times as likely to report using wide brim hats compared to the control stations. When comparing the intervention group at 2 years to baseline, “all the time” sunscreen use increased from 27% to 39% and the use of wide brim hats increased from 27% to 40%.

Overall, this program and its evaluation were well designed and implemented. Strengths of this program include the multi-pronged approach and incorporation of multiple theoretical model constructs. The two year follow-up period is longer than that of other programs and allows evaluators to gain a greater sense of how effective the intervention might remain over time. The means of evaluation were also quite robust, incorporating multiple objective ways to validate self-reported measures.

A lack of information regarding the effect of the program on rates of skin cancer is the primary weakness of this study. The other significant weakness of this study is that the evaluation was not designed to assess the efficacy of individual components. As a result, it is difficult to anticipate how each individual aspect of the program may have contributed to the results.
Sunscreen in Transplant Patients

Sunscreen in Transplant Patients was a study designed to assess whether wearing sunscreen improved prevention of skin cancer among transplant patients\textsuperscript{21}. Because of ethical concerns, they could not create a comparison group of transplant patients that did not receive recommendations to wear sunscreen. Instead, they provided education, cues to act, and free sunscreen to program participants and education only to the comparison group.

In this study, a group of 60 organ transplant recipients received a program including written and oral information on sun protection as well as free sunscreen. They also received training on how to properly apply sunscreen. A matched comparison group received the same written and oral information on sun protection but comparison group participants were responsible for obtaining their own sunscreen and were not trained how to properly apply sunscreen. Recognizing barriers to sunscreen use such as ease of application and cosmetic effects, a preliminary study was used to identify which sunscreen out of five different products was deemed most favorable among a small group of transplant patients prior to using the sunscreen in this program. The sunscreen identified was SPF >50, high-UVA absorption, and a liposomal formulation.

Participants who received free sunscreen completed a diary of all sun protection measures used including frequency and amount of sunscreen use. The reported amount was corroborated by counting the number of sunscreen bottles distributed. After 24 months of follow-up, researchers evaluated the incidence of new actinic keratoses, invasive squamous cell carcinomas, and basal cell carcinomas on areas of skin that received daily sunscreen application.

Over 24 months, the free sunscreen group applied sunscreen an average of 5.6 times per week, year round. At the two-year follow-up, there was a significant difference in development
of precancerous and cancerous lesions between the two groups. In the comparison group, 42 patients had developed 82 new actinic keratosis lesions. In the sunscreen group, 102 actinic keratoses spontaneously resolved, and no new ones were present. Eight people in the comparison group developed new invasive squamous cell carcinomas compared to none in the free sunscreen group. There was no statistically significant difference between the rate of BCC development in the free sunscreen and the control groups. Two BCCs occurred in the free sunscreen group and there were 9 in the control group.

A significant strength of this program is a substantial reduction in the most important outcomes of interest (development of cancer and pre-cancer) over two years. Program coordinators also addressed some of the barriers to sunscreen use such as ease of use and cosmetic effects. Very little detail was provided regarding what the educational materials included, so it is difficult to comment on the content of the educational portion of the intervention.

One weakness of the program is that though they matched individuals in the free sunscreen and comparison groups based on six factors, it is not entirely clear based on the information provided in the article whether the two groups would have had similar skin cancer outcomes if not for the free sunscreen program. Other weaknesses of the program are primarily due to the potential for confounding effects when considering which portion of the program was effective. Factors that may have affected how likely the program participants were to use sunscreen could include that the sunscreen was free, that it was a desirable formulation, and that they kept a diary of their sunscreen and sun protective behavior use. Because the comparison group did not get specific advice regarding how to find that same “desirable formulation” sunscreen, did not keep a diary (i.e. did not have that regular cue to act), and did not receive
training in how to apply sunscreen, it is difficult to determine whether the free sunscreen was the primary discerning aspect. Nonetheless, with components of the program taken together, the results were impressive.

**Specialist Dermatology Clinics**

This study was designed in order to assess whether attending a specialist dermatology clinic in London affected levels of compliance with sun protection measures and awareness of skin cancer risk in renal organ transplant recipients. After transplant, participants were given advice about sun protective measures by the renal transplant team. All renal organ transplant recipients were then referred to the physician-led specialist dermatology clinic within 6-12 months of transplantation. They were recommended to attend the dermatology clinic annually after that.

At the initial dermatology clinic visit, individuals’ risks were determined using a detailed history and full clinical examination by a dermatologist. They were then counseled about their risk for skin cancer and advised on sun protective measures and skin self-surveillance. Sun protective measures discussed include detailed information on sun avoidance, use of photoprotective clothing, and application of high SPF sunscreen on all exposed body parts daily from at least April to October. Practical advice about types of sunscreen was provided. Patients additionally received supplementary written information.

To evaluate the effect of attending this clinic, white-skinned patients under long-term follow-up in the renal transplant clinic between August 2004 and April 2005 were selected for a survey. Seventy-three percent of those invited to participate responded. The mean time since transplant for all participants was 12.9 years, and 89% had attended the dermatology clinic at least once following transplant. The survey included questions about where patients received...
information on photoprotection, the nature of the advice, what sun protective measures they used, and their understanding of why they were in need of extra photoprotective measures. Repeat questionnaires were sent to patients who had not responded within 6 weeks. If answers in the questionnaires were unclear, patients were contacted by telephone to clarify their responses.

The 11% of survey respondents who had never attended the specialty dermatology clinic (non-attenders) were somewhat different from those who had attended the clinic at least once (attenders). Of those who had never attended the clinic, none had been previously diagnosed with skin cancer. In contrast, 30% of those who had attended the clinic reported a history of skin cancer. On average, non-attenders also had a shorter time since transplantation (roughly 9 years compared to 13 years). Based on the survey results, those who had attended the clinic at least once had more knowledge about their skin cancer risk and reported increased sun protective behaviors compared to non-attenders. Of clinic attenders, 95% reported wearing sunscreen and 66% reported wearing SPF >25. In comparison, 68% of non-attenders reported wearing sunscreen and only 43% used SPF >25. Seventy-one percent of attenders were aware that skin cancer was the reason for additional skin protective behaviors compared to 42% of non-attenders.

Attendance at the dermatology clinic was correlated with improved knowledge of skin cancer risk and use of sun protective behaviors, and strengths of the program include providing tailored and periodic education over a long period of time. However, the evaluation of this program has several significant weaknesses. Primarily, it is impossible to know whether attendance at the dermatology clinic resulted in improved knowledge and altered behaviors or whether individuals who were more concerned about skin cancer risk were more likely to seek
information, use protective behaviors, and attend the clinic. That there were significant
differences between the clinic attenders and non-attenders, including much lower rates of
previous skin cancer among non-attenders, raises the suspicion that the comparison might not be
valid. Given these differences between attenders and non-attenders, an alternative explanation
for their observation may be that the individuals who have a history of skin cancer are both more
likely to go to a dermatologist and more likely to engage in sun protective behaviors. An
additional weakness in the evaluation is that 27% of patients asked to participate did not respond
to the survey, introducing potential that important information may not have been collected from
this subset of individuals.

**Educational Outcomes Regarding Skin Cancer in Organ Transplant Recipients: Intensive vs Standard Education**

A program of intensive skin cancer prevention education for organ transplant recipients
was conducted for roughly 101 patients at the von Liebig Transplant Center at the Mayo Clinic\textsuperscript{28}. The intensive skin cancer prevention education included initial education after transplant
followed by repetitive educational mailings. The initial episode-of-care based education
included personalized discussion of risk factors, as well as instructions to use sunscreen with a
sun protection factor of 15 or higher on all exposed skin daily, to wear hats and protective
clothing, and to avoid peak UV light year-round. Participants were advised not to tan outdoors
or indoors. They were also recommended to perform monthly skin self-examinations and notify
a health care provider if they noted any changing areas. The comprehensive Mayo Clinic
pamphlet *Skin Cancer and Organ Transplant Recipients* was given to each patient.

Participants were sent a packet of materials at 2, 6, and 9 months after their initial
education. The packets included a cover letter encouraging careful review of the enclosed
pamphlets. At two months, the pamphlets included were the Skin Cancer Foundation pamphlets *Simple Steps to Sun Safety* and *Skin Cancer: If You Can Spot It, You Can Stop It*. At 6 months, patients received the American Academy of Dermatology pamphlet *Skin Cancer—An Undeclared Epidemic* and leaflet *Stop—Look for Danger Signs in Pigmented Lesions of the Skin*. At 9 months, the Mayo Clinic pamphlet *Skin Cancer and Organ Transplant Recipients* was sent.

In order to evaluate this program, a 101 person comparison group comprised of OTRs who only received the initial in-person education was formed. Baseline information obtained from both program participants and the comparison group individuals included knowledge, use of sun protective measures, intent to change, and perceived barriers to behavior change. Follow-up questionnaires assessing knowledge and use of sun protective behaviors were mailed to each OTR at 3 and 10 months after the initial education intervention.

There were some potentially important differences between the program participants and the comparison group. Prior to starting the program, 29% of the intensive education group compared to 22% of the comparison group reported already practicing sun protection. Another 56% in the intensive group compared to 52% in the standard education group reported intention to implement additional sun-protective behaviors in the next 6 months. Whether these differences were statistically significant was not reported.

Both groups had similar high knowledge scores at baseline, 3-, and 10-months. Prior to the start of the program, they also had similar scores on the assessment of sun-protective behaviors. However, those who received the intensive education materials scored substantially higher on the behavioral assessment at 3 and 10 months, a difference which was statistically significant. In particular, the median behavior score (lower is better) for patients in the intensive program was statistically significantly lower than in the standard group at both follow-ups.
Nonetheless, reported skin self-examination did not follow that trend. At baseline, 38% of intensive program participants reported preforming monthly self-skin exams compared to 41% in the comparison group. At 10 months, 58% of patients in the intensive program reported doing a monthly skin self-examination compared to 68% in the comparison group. Thirty-seven percent and 26%, respectively, reported they intended to start. Among both groups, there was a substantial gap between level of knowledge and use of sun-protective behaviors.

Overall, the intensive education program was associated with higher rates of sun protective behaviors at follow-up, but this may have been partly due to differences between the two groups. Prior to starting the program, more renal transplant recipients in the intensive education group than in the comparison group reported the intent to add sun protective behaviors in the next six months. This makes it difficult to know whether the improvement in reported use of sun protective behaviors on follow-up surveys was due to the program materials or the individuals’ intent to change behavior prior to the start of the program. Other shortcomings of this program include depending on self-reported behavior in the evaluation and not being able to determine whether changes in sun protective behaviors correlated with lower rates of skin cancer. Because knowledge of skin cancer risk and protective behaviors was high before starting the program, it is not possible to assess whether the program would have been effective at improving OTR knowledge of skin cancer risk and how to reduce it.

Strengths of this program include focused efforts on multiple theoretical model concepts including perceived threat and barriers to action from the Health Belief Model and readiness to change from the Stages of Change model. The evaluation of this program was relatively strong because of using a fairly similar comparison group, assessing both knowledge and behavior, and conducting surveys at multiple time points.
Project SCAPE

Project SCAPE is a program designed to provide mailed, tailored information on skin cancer prevention and skin self-examination behaviors. Primary care clinics in Honolulu, HI, and Long Island, NY, recruited adults at moderate to high risk of developing skin cancer for participation. Roughly 360 patients ultimately received the tailored program.

In order to provide customized feedback to participants, individuals’ risk levels were determined using a previously developed brief skin cancer risk assessment tool. Additional information was collected such as reported sun exposure, sun protection and skin examination behaviors, readiness to change, barriers to change, and extent of sunscreen application. Participants received three packages in the mail sent at 2-week intervals. They also received UV self-monitoring aids, instructions for skin self-examination, and information about skin cancer prevention and detection.

In order to assess the efficacy of this program, a randomized controlled trial was conducted in which control group participants received a single mailing with a sun safety booklet, a sheet on sunscreen use, and a bookmark encouraging skin self-examination. Participants in the tailored program and the comparison group completed a sun habits survey at baseline including information about demographics, knowledge of skin cancer, sun exposure, sun protection, and history of performing skin self-examination. They completed a sun exposure diary on two weekdays and two weekend days including information such as using sunscreen, wearing a hat, staying in the shade, and covering up. Telephone interviews were also conducted to ask about sun exposure and protection habits in the preceding weekend and inquire about reactions to the intervention materials. Questions about reactions to the interventions were also included in the follow-up sun habits survey conducted at some point after the program materials.
were mailed. Information about the timing of the follow-up survey and sun diaries was not available. The final number of participants in the trial was 724, and over 80% of those who initially completed the baseline survey completed it. The program group and control group were very comparable after randomization.

Analysis of the survey results showed an increase in sun protective behaviors and reduction in sun burns and overall sun exposure in both groups. However, those who received the tailored, mailed program had a greater increase in sun protective behaviors including the use of sunscreen, hats, and sunglasses use than those who received the single, non-tailored education packet. Of note, location appeared to play an important role. In the Honolulu portion of the program, people in the control group also significantly increased their sun protective behaviors leading to a small difference between the two groups. In Long Island, the tailored intervention group had a much more significant improvement in sun protective behaviors than the control group. Reported rates of skin self-examination increased in both groups, but the effect was more pronounced in the tailored education group. Additionally, individuals at highest risk were more likely to report beginning to do skin self-examination than those who were at moderate risk of developing skin cancer. On the program evaluations, the tailored group respondents were more likely to report having received the materials, read all of them, and kept them. They also rated their materials much higher on average than those in the control group.

Strengths of this program include inclusion of tailored materials, consideration of people in two geographically distinct locations, inclusion of a large number of people, a thorough evaluation, and low cost per person. Though their evaluation was primarily limited to self-report, they used multiple methods to evaluate results including surveys, sun diaries, and
telephone interviews. They also went a step farther than most programs and assessed number of reported sun burns.

It would have been helpful if information about timing of evaluation measures was included in this program write-up. Because it is unknown when the surveys, diaries, and telephone interviews were conducted, it is not possible to know whether improvements in sun protective behaviors were maintained over a long period of time. Another drawback is the lack of assessment of the individual components of the program. While the evaluation intended to determine the effectiveness of the tailored skin cancer risk information, the comparison group also differed from the tailored education group in terms of intensity of mailings.

**REACT Skin Self-Examinations**

This study was design to assess whether providing renal transplant recipients with a skin self-examination workbook including an easy to remember mnemonic improved reported rates of SSE. Participants could not be under the care of a dermatologist or have a history of skin cancer. They also had to have undergone transplant either 1 to 1.2 years or 3 to 7 years prior to the study. Three to seven years after transplant is the time window just before SCC typically develops and 1 year after transplant was previously identified by the authors as an ideal time for SSE education.

Out of 80 individuals who met criteria to participate, 38 were randomized to receive the program, which consisted of reading the REACT workbook in addition to regular education. Another 37 were randomized to the control group in which they received education as usual during their physician visit. Five declined to participate because of insufficient time on the day of the visit.
The REACT mnemonic was developed after conducting a systematic review of the literature in order to identify clinical features most commonly associated with SCC. The mnemonic was:

- Red rough spot
- Evaluate the spot (if possible, invite a partner to check hard to see places)
- Act if the rough red spot…
- Changes in
  - Size = diameter increases rapidly in a few weeks
  - Bleeding = easy bleeding
  - Texture = firm, rougher, develops a bump or an open sore
  - Tenderness = slight pricking sensation becomes a sharp stab when something brushes over the spot
- Tell your doctor

The REACT workbook consisted of the REACT mnemonic along with 6 other sections dedicated to providing knowledge and building skills. These sections included information about anti-transplant rejection medications as a risk factor for SCC, how to identify actinic keratoses, the importance of early detection, and the REACT mnemonic. They also included an assessment of personal sun exposure, exercises to recognize actinic keratoses, and actions to take if a suspicious area was noted. The workbook was refined using cognitive interviews (n=25) until the last 10 participants did not suggest any changes.

In order to evaluate the efficacy of the workbook, all participants completed a baseline self-report survey assessing sun exposure, knowledge, cancer concerns, attitude toward SSE, self-efficacy for recognizing SCC, SSE behaviors, and likelihood of asking a partner for
assistance. Immediately after reviewing the brochure, intervention group participants completed the survey again and also answered questions about their likelihood of performing SSE in the next month. Those in the control group did not retake the survey during their visit. One month after entering the study, participants from both groups responded to a telephone interview.

At baseline, there was no significant difference in sex, education, skin type, or race/ethnicity between the intervention and control groups. There were also no differences between groups with regard to skin cancer knowledge or concern, self-efficacy for detecting SCC, or checking their face for skin cancer in the past month. Control group participants were statistically significantly younger compared to intervention group participants (median age 57-versus 64-years-old). They were also statistically significantly more in favor of SSE and more likely to have checked their body for signs of skin cancer in the past month. There were no statistically significant differences between the subgroups of patients who underwent transplant from 1 to 1.2 years or 3 to 7 years before the study.

Among intervention group participants, the improved knowledge between baseline and the immediate post-workbook survey was statistically significant. Concern about SCC, reported importance of SSE and partner help with SSE, and confidence in recognizing an SCC were also statistically significantly increased. After reviewing the workbook, approximately ¾ of individuals reported they would start examining the face and the body in the next month.

Twenty-two percent of those in the control group checked their skin after the visit compared to 89% of those in the intervention group. No new areas of concern were identified among control group participants in the month after the clinic visit, but 35% of intervention group participants found areas of concern and made an appointment with a dermatologist.

Comparing the two subgroups (those transplanted 1 to 1.2 years prior to the intervention and
those transplanted 3 to 7 years prior to the intervention), there was no significant difference in skin checking or contacting the dermatologist if an area of concern was noticed. However, the 3-7 year group was much more likely to find concerning areas compared to the 1-1.2 year group.

Overall, this program and its evaluation were conducted extremely well. A major strength of the program is the high quality methods used to develop the workbook. Strengths of the evaluation include the use of a similar comparison group, measurement of both knowledge and attitudes, and measurement at three time points. Additionally, a high participation rate increases the likelihood that participants were truly representative of the target population.

Some statistically significant differences between the groups raise concern that randomization was not entirely effective and introduce some possibility of confounding. Not surveying the control group at the end of their clinic visit is another weakness of the study. Observed differences between the intervention group pre- and post-surveys may be partly or fully due to taking the pre-survey. Lower rates of post-visit SSE reported by the control group compared to the intervention group could be partly because more control group participants had already performed SSE recently prior to the visit. However, very high rates of reported post-visit SSE and identification of several suspicious lesions in the intervention group make it less likely that the difference in reported SSE between groups was entirely due to baseline differences. A final weakness of the study is reliance on self-reported history of SSE rather than a more objective measure. However, it would be difficult to identify a more objective measure of SSE, and self-report of SSE is strengthened by the fact that many concerning lesions were identified after administering the program.
Analysis

Considering these six programs can do a great deal to advise the development of the Skin Cancer Prevention Initiative. Even though there were differences in approach and target audience, all programs showed some promise of improving the use of sun protective behaviors or skin self-examination behavior\(^\text{21,25,27-29,31}\). Some of the programs showed gains in skin cancer prevention or SSE knowledge\(^\text{27,28,31}\), and one program evaluation showed reduced development of skin cancer\(^\text{21}\). Despite the fact that the target audiences of these interventions are different, the process for educating patients and promoting increased use of sun protective behaviors is likely to be similar across groups and applicable to OTRs at UNC.

Key Elements

Taken together, the programs had many similar elements. All programs provided general information about skin cancer risk and steps individuals can take to prevent the development of or progression of skin cancer\(^\text{21,25,27-29,31}\). Three of the programs—Specialist Dermatology Clinic\(^\text{27}\), Intensive vs Standard Education\(^\text{28}\), and Project SCAPE\(^\text{29}\)—additionally provided assessments of individual risk by a health care provider. Project SCAPE, the only program comparing individualized education versus general education, found greater improvement in sun protective behaviors with the individualized education, although that could be confounded by the more intensive nature of the individualized program compared to the general education program\(^\text{29}\). Four programs included cues to act on sun protective behaviors either as an intentional program component or through requiring a sun diary for the evaluation process\(^\text{21,25,28,29}\). Free sunscreen was a central component of both the Project SUNWISE\(^\text{25}\) and the Sunscreen in Transplant Patients\(^\text{21}\) programs. The results of the Sunscreen in Transplant Patients Program suggest that providing free sunscreen, particularly sunscreen selected to be of a
desirable formulation, along with instructions to keep a sun diary and directions for proper application, has the potential to significantly reduce skin cancers in the OTR population. Both the Intensive vs Standard Education Program\textsuperscript{28} and Project SCAPE\textsuperscript{29} incorporated repeat educational mailings as a key portion of their programs. The REACT skin self-examinations program combined comprehensive education geared to improve general knowledge of skin cancer risk and SEE with detailed and memorable information about when to suspect SCC\textsuperscript{31}. It also included clear information about actions that patients should take to protect themselves from skin cancer.

**Implications for the Skin Cancer Prevention Initiative**

In considering how best to design the SCPI, nearly all components of these programs could be included. Assessment of individual risk could be conducted at the UNC Dermatology Clinic. Additional information about skin cancer risk for transplant patients and specific steps to reduce an individual’s risk of skin cancer could be provided at the transplant clinics, at dermatology visits, and through repeat mailings in between appointments. The repeat mailings would increase the intensity of the educational intervention while also providing cues to act. Asking SOTRs to fill out sun diaries might also provide a cue to act and motivation to take steps towards sun protection if they could be obtained. Providing free sunscreen and hats to transplant patients could be a useful component to add to the program, but could be logistically more challenging. Either funding or insurance coverage would need to be obtained for both items. If funding could be obtained, sending patients home with a hat would likely be feasible. However, it may be difficult for individuals to carry home sufficient sunscreen at once to last them a year once their appointments become less frequent. If free sunscreen were obtained, another method of distribution, such as through the mail, might need to be used. Finally, teaching patients to
perform SSE using clear and memorable methods may hasten detection of skin cancers that arise between visits and empower SOTRs to take a more active role in their own care.

**Evaluation**

With regard to evaluation methods used in the above programs, the five programs with moderate to high quality evaluation all used some form of controlled trial\(^{21,25,28,29,31}\). While the controlled trials are a higher quality of evaluation than many other types, they are also logistically much more challenging to accomplish and may be beyond what is feasible for this program. However, surveys, telephone interviews, and sun diaries may be effective components for SCPI evaluation and inclusion of a skin cancer assessment with and without the program would be the gold standard if it can be accomplished.

**Conclusion**

A review of the literature revealed six programs with similar goals as SCPI that all showed promising results in terms of increasing sun protective behaviors. While four of the programs focused on OTRs\(^{21,27,28,31}\), two others had different target audiences\(^{27,29}\). There were some similarities in program components such as skin cancer education, but there were also fairly divergent components as well. Overall, it is extremely difficult to tease out which components of the programs may have been the most effective as none used serial evaluation or quality improvement techniques to address the usefulness of each component. However, taken as a whole, the programs offered considerable promise for reducing skin cancer risk and the majority of the interventions could be incorporated into the SCPI.
III. PROGRAM PLAN

Program Overview

Squamous cell carcinoma is the most common cancer to develop after solid organ transplant\(^2\). It is much more likely to be invasive\(^{11-13}\) and metastatic\(^{14}\) than in the general population. SOTRs are also at elevated risk of developing BCC\(^3,6\) and may have an increased risk of developing melanoma\(^6-8\). The presence of modifiable risk factors related to UV exposure creates an opportunity to educate transplant recipients about how to reduce their skin cancer risk. Early detection through total body skin examinations performed by health care professionals and skin self-examinations could reduce the need for potentially disfiguring surgery as well as the risk of metastasis.

In response to needs identified at the University of North Carolina, the Skin Cancer Prevention Initiative will create a collaborative program between UNC’s transplant clinics and Department of Dermatology in effort to improve prevention and early detection of skin cancer among UNC’s solid organ transplant recipients. Key components of the program include (1) streamlined referrals to dermatology, (2) risk assessment and individualized risk communication (3) providing each transplant clinic with appropriate educational materials and guidelines, (4) education about skin cancer risk and sun protective behaviors provided through multiple sources both before and after transplant, and (5) free hats and sunscreen provided to transplant recipients. The end goal of the program is to reduce the negative effect of skin cancer on quality of life and mortality for these individuals.

Program Context

In order to develop a comprehensive skin cancer prevention program for UNC’s transplant recipients, the context of the program must be carefully considered to identify potential
challenges to implementation. To be successful, the program must be technically feasible as well as acceptable to both providers and recipients. Considering program stakeholders in advance can allow involvement of appropriate parties in both program design and evaluation.

**Political Environment**

The economic recession has significantly affected government funding in the public health sector. Despite continually rising health care expenditures, the Centers for Disease Control and Prevention (CDC) budget decreased from $7.31 billion to $6.13 billion between 2005 and 2012. State and local public health budgets have also been cut dramatically. Between 2008 and 2012, the median per capita state spending on public health decreased from $33.71 to $27.40. As a result, there is both a demand to promote population health in an affordable manner and less available funding to sponsor new programs.

**Consistency with Local, State, and National Priorities**

Within UNC, many different groups promote skin cancer prevention. The UNC Center for Environmental Health and Susceptibility has partnered with multiple local organizations including news sources to develop educational materials and increase public awareness about skin cancer risk and prevention. Within each of the transplant clinics, some level of skin cancer prevention education is already in place. Considerable skin cancer research, particularly related to melanoma, is conducted at UNC’s Lineberger Comprehensive Cancer Center and the Department of Dermatology.

North Carolina, the state in which the program will be initiated, has among the highest rate of melanoma in the US, at between 23.1 and 32.6 cases per 100,000 people. In response growing concerns about skin cancer, North Carolina passed the Youth Skin Cancer Protection Act in May of 2011 in an effort to limit minors’ use of indoor tanning beds. Increasing rates of
skin cancer across the nation have also prompted recognition by several national agencies. Healthy People 2020 set increasing the use of sun protective behaviors as one of the nation’s health objectives\textsuperscript{37}. The CDC leads national efforts to reduce skin cancer through education of the public about skin cancer risk and prevention\textsuperscript{38}.

Despite the evidence that skin cancer prevention is consistent with local, state, and national priorities, the elevated skin cancer risk and particular susceptibility to SCC among transplant recipients is not widely recognized. As a result, improving awareness of skin cancer risk in SOTRs is likely to be an important step in gaining support for this program.

\textit{Acceptability to Stakeholders and Feasibility}

Key stakeholders in the SCPI program include the transplant recipients as well as the staff at all involved clinics. To ensure acceptability to each of the transplant clinics as well as the Department of Dermatology, I conducted interviews with key staff members from each clinic to identify needs, preferences, and resource limitations. For instance, because transplant clinics are responsible for monitoring and addressing many different aspects of health for SOTRs, taking multiple steps to complete a referral or providing extensive education solely devoted to skin cancer prevention in the transplant clinics may not be feasible. The dermatology clinic is also busy, and risk assessment tools and educational materials should be straightforward and easy to integrate into the existing clinic structure. Additional feedback on program efforts will be obtained through formal (interviews, surveys, and focus groups) and informal (open lines of communication) means. By reviewing the literature, I identified preferences of SOTRs at other sites and used them to guide the initial program plan for the SCPI. Feedback from UNC’s transplant recipients will be a key component of evaluation efforts.
Resource needs and technical requirements of the SCPI program are relatively small because the program will be housed within an existing department (the Department of Dermatology) at UNC and the bulk of education will be provided at the time of standard medical appointments. A high priority will be to streamline the program within the constraints of medical appointments without putting undue stress on health care providers or overwhelming the patients. The program will require a small amount of administrative staffing as well as additional staffing during peak evaluation periods. Minimal additional funding will be required to pay for repeat mailings. The primary funding challenge will be obtaining free hats and sunscreen for distribution to transplant recipients.

**Other Potential Barriers**

Research has shown that SOTRs report considerable mental distress after transplant\(^{39}\). In the immediate post-transplant period, SOTRs are faced with recovering from surgery, the possibility of acute transplant rejection, multiple medical visits, and increased risk of infection. In a series of focus groups and cognitive interviews of recent transplant recipients, Kim et al. determined that the optimal time after transplant to provide skin cancer education was 1 year after transplant\(^ {32}\). Prior to that, SOTRs were too overwhelmed with other aspects of post-transplant care. However, because of the risk of acute organ rejection, SOTRs’ level of immunosuppression is highest in the first few months after transplant. As a result, they may be at the highest risk of acquiring cancer-promoting sun damage during that period. To address this issue, the SCPI will begin emphasizing skin cancer risk and prevention well before SOTRs undergo transplant.

Because many of UNC’s SOTRs have traveled from other areas of North Carolina, skin cancer prevention efforts at the local level in a single county or town are unlikely to affect the
majority of transplant patients. Unfortunately, the culture of many areas of rural North Carolina tends to favor higher levels of outdoor activity without substantial efforts to use sun protection (personal observation but no data available). As a result, encouraging transplant patients to use sun protective behaviors may require them to depart significantly from the behaviors they have engaged in throughout their lives and the behaviors of those around them. While a shift of attitudes towards sun protective behaviors across North Carolina is beyond the scope of this program, educating family and friends who accompany the SOTRs to clinic might promote positive attitudes skin cancer prevention among the patients’ closest contacts.

**Financial Resources**

Possible financial resources for developing and putting in place a program include The Skin Cancer Foundation, the Prevent Cancer Foundation, the American Cancer Society, the American Skin Foundation, Blue Cross Blue Shield and the Center for Disease Control. Insurance companies could potentially serve as a financial resource for patients by covering sunscreen and protective clothing such as hats. This would require collaboration with and buy-in from insurance companies but would potentially lower the threshold to act for transplant patients. Collaborating with manufacturers may also be a way to obtain free or discounted sunscreens, wide brim hats, and sun protective clothing.

**Program Theories**

In order to design the most appropriate program plan and evaluation strategy, I identified components of different behavioral change theories as tools for promoting change. I selected both individual and intrapersonal level theories because the primary goal of the program is to promote change at the individual level or at the level of their immediate environment. The
selected theories include: the Health Belief Model (HBM), the Precaution Adoption Process (PAPM), and Social Cognitive Theory (SCT).

The Health Belief Model is based on the theory that individuals’ decisions to adopt health behaviors are based on their perceptions of their individual risk of a bad outcome and the benefits of trying to avoid that bad outcome. There are six main constructs to the theory, including: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. Clowers-Webb, et al. used components of the HBM in designing their skin cancer prevention education program for transplant recipients. Their primary methods of promoting behavioral change were to educate patients about their elevated risk of skin cancer, the seriousness of skin cancer in immunosuppressed patients in particular, and the efficacy of using sun protective measures in reducing that risk. They used repeated mailings at 3-4 month time intervals to provide cues to action and included in these mailings pamphlets such as “Simple Steps to Sun Safety and Skin Cancer: If You Can Spot It, You Can Stop It” with messages promoting self-efficacy. They also assessed patients’ perceived barriers to taking action in an attempt to inform future program plans. Using all constructs of the HBM is likely to be beneficial in this program plan, just as it was in theirs. The HBM constructs could also guide evaluation efforts. Surveys of patients in the program assessing where their beliefs fall within the HBM constructs could guide where program efforts should be more concentrated.

The Precaution Adoption Process Model is another theory focused on individual level change that identifies seven stages in the journey from lack of awareness to adoption and/or maintenance of a behavior. It builds on the Stages of Change model by expanding on the stages preceding active decision-making and recognizing the differences between individuals who have decided not to act and those who are unaware of or unengaged by an issue. The
PAPM stages include: unaware of issue, unengaged by issue, deciding about acting, decided to act, acting, and maintenance. While some constructs between HBM theory and PAPM theory are similar, such as awareness of the issue and concern about the issue being required to decide whether to act, there are some key differences between the theories. The PAPM recognizes a precontemplation phase which says that even though someone is aware of an issue and concerned about it, they have not necessarily decided to act to take steps against it. It also recognizes other important steps in the process such as beginning to act and maintaining that action. Since sun protective behaviors require daily action on the part of the individual, the stages of acting and maintaining are crucial steps this program must address in order to effectively promote behavior change. Assessing action and maintenance of action in program evaluation will also be important in determining whether the program is meeting its goals. No skin cancer prevention programs for transplant patients have used this theory and so appropriate models for promoting sun protective behaviors in the general public are currently being identified in the literature.

Social Cognitive Theory is based on the premise that human behaviors are not determined in a vacuum—they are affected by both personal factors and the environment around that person. The specific constructs of SCT that will be used for the development of this program plan include reciprocal determinism and observational learning. Reciprocal determinism, which recognizes the interaction between the person, behavior and environment in which the behavior is performed, forms a basis for making adjustment to the individuals environment and influencing personal attitudes. In the case of this program, encouraging family members and close friends to adopt sun protective behaviors and support their loved ones to adopt them could create an opportunity for environmental adjustments and observational
learning. Additionally, personal attitudes affecting behaviors should be addressed as they can be barriers to behavior change. Such attitudes could include factors such as concerns about appearance—whether patients believe tanned skin looks healthy or find it out of place to wear long sleeves and hats in summer—and whether outdoor activities are best undertaken at mid-day.

A systematic review of programs promoting sun protective behaviors among tourists found that interventions addressing supportive social norms for sun-protective behaviors and those providing appearance-based education about photoaging appeared to be more effective than programs solely addressing educational and self-efficacy factors. This supports the value of using SCT to promote behavioral change.

**Goals and Objectives**

*Goal:* Reduce the negative impact of skin cancer among UNC transplant recipients.

*Short Term Objectives:*

1. By month six, 100% of transplant coordinators at participating transplant clinics will have received a set of tailored recommendations for how their clinic can help patients reduce their risk of skin cancer along with contact information for a project coordinator. This will include published, evidence-based guidelines where possible, as well as a tailored plan designed through collaboration between the transplant clinics and dermatology department based on best available evidence and feasibility.

   **Activities:** Identify all relevant guidelines and evidence-based practices for skin cancer prevention in transplant patients.

   **Activities:** Interview a transplant coordinator from each clinic in order to assess the clinic structure and what program approaches may be most feasible for implementation.
Provide contact information for program coordinators at this visit and encourage continued communication of requests, questions, and concerns.

**Activities:** Consult with dermatologists to determine additional steps where professional guidelines and evidence-based practices are not available.

**Activities:** Collaborate to develop a tailored set of recommendations for each clinic based on guidelines and evidence, dermatologist recommendation, clinic structure, and preferences of clinic staff.

**Activities:** Distribute recommendations to all transplant coordinators within each participating clinic. Follow-up to ensure all transplant coordinators at participating clinics received the recommendations and have no questions.

2. By month 18, 80% of patients added to the wait list at participating transplant clinics will be seen at the UNC dermatology clinic within 6 months of being added to the wait list.

**Activities:** Establish a streamlined dermatology referral process requiring minimal work from transplant clinic staff so that appointments are automatically made for patients on days they have other UNC appointments, if possible.

**Activities:** Add dermatology referral to the checklist used at the time of adding patients to the waitlist.

3. By month 18, 100% of patients who have been seen by dermatology will have their skin cancer risk level documented in their medical record.

**Activities:** Identify evidence-based risk assessment tools that are relevant to waitlist patients and feasible to implement at a busy dermatology practice.

**Activities:** Identify evidence-based risk assessment tools that are relevant for post-transplant patients and feasible to implement at a busy dermatology practice.
Activities: Streamline the identified risk assessment information into a single, easy-to-use risk assessment tool if waitlist and post-transplant risk factors are sufficiently similar. If not, streamline the information into two distinct easy-to-use risk assessment tools.

Activities: Ensure an appropriate system of flagging waitlist and post-transplant patients is in place at the dermatology clinic so that the appropriate risk assessment tool and educational materials are included with patient charts at the time of clinic check in.

Activities: Add a transplant patient template to the electronic medical record system so that physicians in dermatology are reminded to record patients’ risk levels in the system.

4. By year two, patients at participating transplant clinics will attend 75% of recommended dermatology visits.

Activities: Establish a streamlined dermatology referral process requiring minimal work from transplant clinic staff so that appointments are automatically made for patients on days they have other UNC appointments, if possible.

Activities: Provide patient education about skin cancer risk at transplant clinics so that patients consider attending the dermatology clinic to be important.

5. By year two, 80% of light-skinned patients at participating clinics who are more than 12 months out from their transplant will be able to report that they are at higher risk for skin cancer than the general public, identify skin cancer as the reason extra sun protective measures are encouraged, and name at least three steps they can take to reduce their risk of developing advanced skin cancer.

Activities: Locate appropriate reading level educational materials for distribution to patients.
Activities: Establish a timeline and plan for distributing materials (e.g. at transplant clinic visits, dermatology clinic visits, and through periodic mailings).

Activities: Collaborate with transplant clinic staff to make educational materials available in patient rooms and the waiting area.

Activities: Educate transplant and dermatology clinic staff on appropriate skin cancer prevention education to provide to patients at each visit, both before and after transplant.

Activities: Refer patients to dermatology 6 months after their transplant and then at intervals appropriate for their skin cancer risk so that patients are engaged in discussions about their skin cancer risk in a specialty clinic setting as well as receive appropriate skin screenings.

Activities: Add referral to dermatology at the first transplant clinic visit after transplant.

Activities: Collaborate with transplant clinic staff to periodically include skin cancer prevention topics in educational presentations provided to transplant recipients and clinic staff.

6. By year two, 60% of light-skinned patients at participating clinics who are more than 12 months out from their transplant will report that they conduct total body skin self-examinations at least 6 times per year.

Activities: Identify or develop at least one written SSE resource that includes information about the importance of regular SSE, comprehensive and memorable information about how to identify cancerous or precancerous areas (particularly SCC), and clear directions for how to proceed if a concerning area is found.

Activities: Determine when and where to provide written information about SSE.
Activities: Encourage transplant and dermatology clinic staff to promote regular SSE for transplant patients at each visit.

Long Term Objectives

1. By year 3, all transplant clinics at UNC will use this program or a modified version of this program that includes regular and adequate education as well as an adequately regular and streamlined process for referring to dermatology.

2. By year 3, communication will be established between UNC Dermatology and dermatology clinics across the state of North Carolina so that transplant patients can be followed by a dermatologist in their hometown if they prefer but tenets of the SCPI are still promoted at their clinic and UNC Dermatology remains a safety net.

   Activities: Identify as many dermatology clinics across the state of North Carolina as possible.

   Activities: Send the identified clinics a letter about the SCPI and ask them to respond if they would like to be involved.

   Activities: Establish a list of dermatology clinics interested in caring for transplant patients.

   Activities: If a transplant recipient has an existing dermatologist not on that list, send the clinic a letter detailing the SCPI, stating the recommended education and risk assessment, and asking for collaboration.

   Activities: Make it clear to all collaborating clinics that UNC Dermatology has a high-risk skin cancer clinic available if their SOTRs begin to develop multiple cancers.

3. By year 5, obtain free or discounted sunscreen and hats for at least 75% of light-skinned transplant patients at participating clinics.
**Activities:** Meet with Blue Cross Blue Shield (the primary payer for UNC transplant patients aside from Medicare) to discuss feasibility of covering sunscreen and a one-time hat purchase for transplant patients.

**Activities:** Contact hat manufacturers about providing free or discount hats on a one time basis for all transplant patients.

**Activities:** Contact sunscreen manufacturers about providing free or discount sunscreen to transplant patients.

**Activities:** Contact businesses (sunscreen and hat manufacturers, UNC stores, etc) about donating a percent of proceeds from a certain item towards providing sunscreen and hats for transplant patients.

**Activities:** Identify and apply for grants that could provide funding to purchase hats and sunscreen for transplant patients.

4. By year 5, 40% of Caucasian transplant recipients will report always wearing a wide brim hat for outdoor activities and 60% of Caucasian transplant recipients will report applying adequately high SPF sunscreen at least 5 days per week year round prior to going outside.

**Activities:** Incorporate patient family and friends in educational efforts when possible.

5. By year 5, a 20% reduction in invasive skin cancers will be observed among UNC transplant patients.

While the overall goal and primary objectives are expected to remain stable through the development of the program plan and evaluation, specific targets may need to be adjusted after identifying baseline data for this population. Baseline data for a similar population is not available for comparison due to variation in skin cancer prevention programs at different institutions, and relatively little evidence exists to suggest what may be reasonable targets.
Ideally, this program seeks to set lofty but obtainable targets and determine success based on meeting 80% of target measures. These targets may also be adjusted prior to full-scale implementation of the program based on feedback from stakeholders, including transplant recipients, transplant clinic personnel, and dermatology clinic personnel.

**Program Implementation**

**Activities**

The first step of the SCPI will be establishing clear lines of communication between the UNC transplant clinics and Department of Dermatology. We will then develop and distribute tailored recommendations for improving skin cancer prevention education to each transplant clinic based on the clinic’s structure and patient population as well as the best evidence available for promoting sun protective behaviors in transplant recipients. Our other activities will be related to five key program components, including: improving dermatology clinic attendance, conducting risk assessment, improving education about skin cancer risk and prevention measures, and providing free sunscreen and hats. A timeline for how these activities will be implemented is included in Table 1.

*Improve Dermatology Clinic Attendance*

At the heart of efforts to improve rates of dermatology clinic attendance is streamlining the referral system. This will be achieved by having transplant clinics send appointment requests to a single point-person within dermatology who is familiar with scheduling these patients. Patients will no longer have to schedule their own appointment, and their appointment at both clinics will be on the same day when possible, thus reducing barriers to action for SOTRs. Other steps to improve dermatology clinic attendance include adding reminders to transplant clinic checklists at the appropriate times, focusing on patient education so they understand the need for
Table 1: SCPI Implementation Timeline

<table>
<thead>
<tr>
<th>Activity</th>
<th>Staff Involved</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet with UNC Transplant Clinic Coordinators and Dermatology Department</td>
<td>Administrator and Coordinator</td>
<td>Month 1</td>
</tr>
<tr>
<td>Conduct baseline evaluation</td>
<td>Researcher, Administrator, and Coordinator</td>
<td>Month 2-6</td>
</tr>
<tr>
<td>Identify relevant guidelines and evidence-based practices, educational materials and risk assessment tools</td>
<td>Coordinator</td>
<td>Months 2 and 3</td>
</tr>
<tr>
<td>Develop dermatology referral system</td>
<td>Administrator and Coordinator</td>
<td>Month 3</td>
</tr>
<tr>
<td>Develop tailored sets of recommendations for each clinic</td>
<td>Coordinator</td>
<td>Month 4</td>
</tr>
<tr>
<td>Seek feedback on recommendations and distribute final recommendations</td>
<td>Administrator and Coordinator</td>
<td>Month 5</td>
</tr>
<tr>
<td>Conduct orientation/training sessions with all transplant coordinators</td>
<td>Administrator and Coordinator</td>
<td>Month 6</td>
</tr>
<tr>
<td>Streamline risk assessment tools for use at the dermatology clinic</td>
<td>Administrator and Coordinator</td>
<td>Month 7</td>
</tr>
<tr>
<td>Add dermatology referral to waitlist checklist</td>
<td>Administrator</td>
<td>Month 7</td>
</tr>
<tr>
<td>Streamline system for managing patient visits in dermatology</td>
<td>Administrator and Coordinator</td>
<td>Month 7</td>
</tr>
<tr>
<td>Identify additional potential sources of funding and requirements</td>
<td>Administrator</td>
<td>Month 7-8</td>
</tr>
<tr>
<td>Meet with BCBS</td>
<td>Coordinator</td>
<td>Month 7-8</td>
</tr>
<tr>
<td>Contact other potential business collaborators (e.g. sunscreen and hat manufacturers)</td>
<td>Coordinator</td>
<td>Month 7-8</td>
</tr>
<tr>
<td>Complete grant applications</td>
<td>Coordinator and Administrator</td>
<td>Months 9-12</td>
</tr>
<tr>
<td>Conduct initial evaluations</td>
<td>Coordinator and Administrator</td>
<td>Months 9-12</td>
</tr>
</tbody>
</table>
the visits, and establishing a network of dermatologists across the state to provide care to SOTRs who are committed to being followed by a dermatologist in their hometown. After the first visit while on the wait list and the first visit after transplant, dermatology clinic staff will be responsible for scheduling dermatology visits at appropriate intervals for each patient.

Risk Assessment

Conducting risk assessment at dermatology visits will allow health care providers to provide patients with individualized information about their skin cancer risk and help ensure that patients receive total body skin examinations at appropriate intervals based on that risk. We will review existing literature about risk factors and risk assessment tools. Based on that, we will identify or create one to two risk assessment tools that can be used for SOTRs on the waitlist and after transplant. Flagging transplant recipients at the time of dermatology clinic check-in will allow staff to put the appropriate risk assessment tool and educational materials with each SOTR’s chart to ensure their level of risk is determined. Transplant recipient templates (waitlist and post-transplant) in the electronic medical record system will remind physicians to record the individual’s risk in their charts for later reference.

Improve Education About Skin Cancer Risk and Promote Prevention Measures

We will work to improve awareness of and engagement by skin cancer prevention by educating SOTRs at multiple time points, including before transplant and one year after transplant to maximize their ability to absorb the information. The education will include information about skin cancer risk, sun protective measures, and skin self-examination. It will be provided through repeat mailings and by multiple different individuals, including a specialist dermatology clinic where personalized risk information can be discussed. Drawing from the best available literature and guidelines on SOTR skin cancer prevention education will ensure that the
education is the highest quality available. Providing written materials and clearly laying out a plan of education for each clinic will ensure health care providers are aware of the latest recommendations and make it easier for them to engage SOTRs in education. Transplant recipients will also receive lectures on skin cancer prevention periodically within existing lecture series’, and skin cancer prevention educational materials will be placed in the transplant clinic waiting room and clinic rooms. Recognizing that environment and attitudes affect decision-making, we will further promote behavior change by providing skin cancer prevention education to family members and close friends who accompany SOTRs to clinic and by including appearance-based benefits of sun protection in some of the educational materials.

_Free Sunscreens and Hats_

Obtaining free sunscreens and hats is likely to be the most difficult portion of the program. However, evidence that providing free sunscreen may substantially reduce the development of skin cancers in SOTRs also makes it likely to be worthwhile. To achieve this objective, we will meet with Blue Cross Blue Shield about the risk of skin cancer in SOTRs, the evidence for using sunscreen, and the potential for sunscreen coverage in this population to generate cost-savings. We will contact several manufacturers of sunscreens, hats, and other sun-protective clothing in attempt to solicit donations or discounts. We will also apply for grants that could fund the purchase of hats and sunscreen and contact businesses about donating a percent of proceeds from certain items in order to cover the cost of sunscreen and hats.

_Resources Needs_

The Skin Cancer Prevention Initiative is expected to be a fairly low-budget (Appendix A), cost-effective means of promoting skin cancer prevention among transplant patients, largely because it functions within existing systems of care. To meet funding needs, we will apply for
funding from several organizations including: Blue Cross Blue Shield Foundation of NC, Skin Cancer Foundation, Prevent Cancer Foundation, American Cancer Society, and American Skin Foundation.

**Personnel: Total $113,750 over 5 years**

An existing dermatology clinic staff member will receive $10,000 per year to oversee program implementation for all years of the program. A single part-time coordinator (20 hours per week) with a background in public health will be required for the first year to coordinate with clinics, provide training, ensure goals are being met, and oversee evaluations. Additionally, a part-time researcher (20 hours per week) will be required for the first six months to collect relevant background data on the patient population and document important baseline information to contribute to future evaluation efforts. In years three and five, a researcher will need to be hired part-time (20 hours per week) for six months of the year to aid in conducting program evaluations.

**Supplies: Total $25,900 over 5 years**

Brochures and educational materials will be obtained or printed for post-transplant patients at an expected cost of $3 per person per year. Brochures and educational materials for pre-transplant patients will be provided at visits sent through the mail at a cost of $8 every five years ($3 for cost of printing and $5 for mailing). An additional $500 per year for miscellaneous printing and office supplies was included in the budget.

**Total Cost over 5 years: $164,650**

In addition to personnel and supply costs, $5000 per year was included in a discretionary fund to cover unexpected expenses or unanticipated opportunities.
**Logic Model (Table 2)**

**Assumptions**

- Solid organ transplant recipients (SOTRs) are at markedly elevated risk for developing skin cancer, particularly squamous cell carcinoma (SCC).\(^2\)

- Sun exposure is a significant modifiable risk factor for the development of non-melanoma skin cancer among SOTRs\(^{17,19}\).

- Higher rates of aggressive skin cancer have a negative effect on quality of life of SOTRs, and treatment of these cancers incurs substantial cost and use of resources.

- Various surveys have identified deficits in SOTR’s knowledge of skin cancer risk and prevention measures\(^{22,23}\). We assume the use of sun protective behaviors has not yet been maximized among UNC transplant patients.

- Interventions such as regular education\(^{29}\), providing free sunscreen\(^{21,25}\) and hats\(^{25}\), and referring to high-risk dermatology clinics\(^{27}\) has the potential to reduce both development of skin cancer and poor outcomes as a result of skin cancer in the SOTR population.

- Early detection of skin cancers can reduce the need for invasive treatment and reduce the risk of metastasis.
### Table 2: SCPI Logic Model

<table>
<thead>
<tr>
<th>INPUTS</th>
<th>ACTIVITIES</th>
<th>OUTPUTS</th>
<th>OUTCOMES (1-3 YEARS) (3-5 YEARS)</th>
<th>IMPACT (5+ YEARS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People:</td>
<td>Meet with UNC Transplant Clinics and Dermatology Department to gain support and learn about existing clinic structures</td>
<td>Established collaboration between transplant coordinators, UNC Dermatology, and program staff</td>
<td>Short Term (1-3 Years): All transplant coordinators at participating clinics will have a tailored set of recommendations for how their clinic can help patients reduce their risk of skin cancer</td>
<td>Reduced development of skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td>Organizational:</td>
<td>• SCPI staff</td>
<td>• Improved transplant coordinator level of knowledge of skin cancer risks</td>
<td>• 80% of patients added to the wait list at participating clinics will be seen in the dermatology clinic within 6 months of being added to the list</td>
<td>Reduced mortality from skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• UNC SOTRs</td>
<td>• Improved SOTR knowledge of skin cancer risks</td>
<td>• 100% of patients seen in dermatology will be risk stratified, and their risk level will be recorded in their medical record</td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Materials and resources</td>
<td>• SOTRs will receive skin cancer education at transplant and dermatology clinic visits and by mail</td>
<td></td>
<td>Reduced cost of dermatological treatment for UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Organizational resources</td>
<td>• Transplant clinic staff will have triggers for referring to dermatology</td>
<td>• Patients at participating transplant clinics will attend 75% of recommended dermatology visits</td>
<td>Sustained program for SOTR skin cancer prevention at UNC</td>
</tr>
<tr>
<td></td>
<td>• Dermatology clinics across the state</td>
<td>• Dermatology clinic staff will have reminders and tools to risk stratify all patients</td>
<td>• 80% of light-skinned patients at participating clinics will be knowledgeable of their elevated risk of skin cancer and need for additional sun protective measures</td>
<td>Sustained partnership between UNC Transplant Clinics and UNC Dermatology Department</td>
</tr>
<tr>
<td></td>
<td>• Blue Cross Blue Shield (BCBS)</td>
<td></td>
<td></td>
<td>Sustained source of free hats and sunscreen for UNC Transplant Recipients</td>
</tr>
<tr>
<td></td>
<td>• Sunscreen companies</td>
<td></td>
<td></td>
<td>Program expanded to other transplant clinics in need of a skin cancer prevention program</td>
</tr>
<tr>
<td>Collaborators:</td>
<td>• Contact dermatology clinics across the state with information about the SCPI and a request for collaboration</td>
<td>• Education about regular skin self-examination will be provided</td>
<td></td>
<td>Fewer patients who will need treatment for skin cancer</td>
</tr>
<tr>
<td></td>
<td>• Contact dermatology clinics across the state with information about the SCPI</td>
<td></td>
<td></td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Meet with BCBS to discuss feasibility of covering sunscreen and a one-time hat purchase for transplant patients</td>
<td></td>
<td></td>
<td>Reduced cost of dermatological treatment for UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Contact hat and sunscreen manufacturers about providing free or discounted hats or sunscreen</td>
<td></td>
<td></td>
<td>Sustained partnership between UNC Transplant Clinics and UNC Dermatology Department</td>
</tr>
<tr>
<td></td>
<td>• Involve SOTRs’ family and friends in educational efforts</td>
<td></td>
<td></td>
<td>Sustained source of free hats and sunscreen for UNC Transplant Recipients</td>
</tr>
<tr>
<td></td>
<td>• Contact businesses about donating a percent of proceeds from certain items towards sunscreen and hats for transplant patients</td>
<td></td>
<td></td>
<td>Program expanded to other transplant clinics in need of a skin cancer prevention program</td>
</tr>
<tr>
<td>Materials and Resources:</td>
<td>• Contact dermatology clinics across the state with information about the SCPI</td>
<td>• Dermatology clinics across the state that are interested in caring for transplant recipients are identified and made aware of the SCPI</td>
<td></td>
<td>Fewer patients who will need treatment for skin cancer</td>
</tr>
<tr>
<td></td>
<td>• Contact dermatology clinics across the state with information about the SCPI and a request for collaboration</td>
<td>• BCBS and manufacturers are aware of substantially elevated risk of skin cancer among transplant recipients</td>
<td>• Have the program or a variation of the program implemented at all of UNC’s transplant clinics</td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Meet with BCBS to discuss feasibility of covering sunscreen and a one-time hat purchase for transplant patients</td>
<td>• BCBS is aware of potential cost savings that might be achieved from providing sunscreens and hats for transplant patients</td>
<td>• 40% of light-skinned transplant recipients report always wearing a wide brim hat for outdoor activities and 60% report applying adequate quantities of sunscreen at least 5 days per week year round prior to going outside</td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Contact hat and sunscreen manufacturers about providing free or discounted hats or sunscreen</td>
<td>• A sustainable source of hats and sunscreen or funding for hats and sunscreen will be obtained</td>
<td></td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Involve SOTRs’ family and friends in educational efforts</td>
<td>• SOTRs’ close family and friends will be aware of their skin cancer risk</td>
<td></td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Contact businesses about donating a percent of proceeds from certain items towards sunscreen and hats for transplant patients</td>
<td></td>
<td></td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
<tr>
<td></td>
<td>• Contact grant agencies to seek funding that would cover sunscreen and hats</td>
<td></td>
<td></td>
<td>Fewer invasive treatments for skin cancer among UNC SOTRs</td>
</tr>
</tbody>
</table>

N. Moye 44
IV. EVALUATION PLAN

Evaluation Rationale

Evaluation of the Skin Cancer Prevention Initiative is important for several reasons. It will help us determine how effectively different activities are being implemented, monitor progress towards program goals, and ensure acceptability of the program for providers and recipients. It will help program staff identify areas for continued quality improvement and help justify further funding and support. Through publishing, evaluation also allows an opportunity to share with others which aspects of the program are successful, which are not, and how future program designs might be improved.

Evaluator’s Role

For this program, I recommend using an internal evaluator with an external consultant. An internal evaluator has several advantages. Among these are increased familiarity with the inner workings of the program and access to organizational resources. Because this program is based on collaboration between different medical departments, each with their own systems and protocols, an effective evaluator will need to have substantial insight into the program and collaborating departments. Additionally, the evaluator should be familiar with transplant recipients in order to address unique challenges of providing them with care. An internal evaluator is also more likely to establish good rapport with program staff. This may help them obtain informal feedback about the program to guide the evaluation process and may promote increased stakeholder involvement in the evaluation process. However, it may also make it more challenging for them to discuss areas in need of improvement with program staff. Adding an external consultant provides a third-party viewpoint about program activities and needed evaluation activities. This can be important both to provide fresh perspective and to help ensure
that an internal evaluator is not overly swayed by his or her relationship with other program staff. Additionally, it may be easier to identify an external consultant with a high level of technical expertise in program evaluation than it would be to identify an internal evaluator with that expertise. As a team, the evaluators should be observant, flexible, good at communicating and problem solving, and skilled in evaluation and research methods. They must also keep in mind that the most important goal of the evaluation is to obtain useful information.

**Stakeholders**

All key stakeholders—including transplant clinic staff, dermatology clinic staff, and transplant recipients—should be involved in the evaluation process. If the program is not functioning well for any of these key groups, it will fail to be optimally successful and may fail completely. Both transplant clinic staff and dermatology clinic staff are likely to be concerned with fitting the program seamlessly into their existing clinic structure. Because of busy clinic schedules, a program that requires too many extra steps or too much time is not likely to be maintained for long. For transplant clinic staff, this is likely to be even more important since they must address a multitude of medical issues at each clinic visit. For both clinics, the program’s standard procedures will need to be easy to disseminate to the many different personnel required to make it run smoothly. Because transplant recipients are likely to have other priorities besides skin cancer prevention, they may be most concerned with how material is presented and whether its presentation dramatically increases the stresses associated with transplantation. A variety of methods can be used to involve all of these stakeholders in the evaluation process, starting from the initial design of the evaluation plan. Feedback from transplant and dermatology clinic staff could be obtained through informal discussions, formal interviews, focus groups, and surveys. Maintaining open lines of communication between
program staff and other clinic staff will be a key means of identifying areas for potential improvement. Information from transplant recipients could be obtained primarily through focus groups and surveys.

**Potential Challenges**

In the process of conducting this evaluation, we will undoubtedly come across challenges. Because the program involves so many different clinics, there are certain to be many different perspectives on what is important that will need to be addressed. Additionally, what works well for one transplant clinic may work very poorly for others, so determining how well the program works for each of the different transplant clinics will be important. The busy nature of the dermatology and transplant clinics may also make it difficult to conduct evaluations during or between patient visits.

The transplant recipient population also poses challenges. Many of the individuals do not use internet and may have varying levels of literacy. As a result, evaluation methods must be structured in such a way that many transplant recipients are able to give high quality feedback about the program. Because knowledge about skin cancer is not directly correlated to sun protective behaviors, the two will need to be measured separately in the evaluation. Finally, we must take into account that the outcomes of primary interest (reducing the burden of skin cancer in this population) are likely to be removed from the intervention by a few years. In the interim, we will have to evaluate intermediate outcomes. When skin cancer related outcomes begin to appear in a few years, we will need to use appropriate methods to reduce the likelihood of confounding.
Evaluation Design

The goal of comprehensively evaluating the Skin Cancer Prevention Initiative is to determine how effectively the program is meeting its goals and objectives. The evaluation should include measures of both implementation and outcomes, and it must also be feasible to conduct. To evaluate the program implementation and outcomes, we will use components of both quasi-experimental and observational designs.

One Group Pre- and Post-Test Design

The first quasi-experimental design we will use is a one group pre- and post-test design. The reason for conducting a pre-test assessment is to generate baseline comparison data that can be used to compare post-test performance. The data will be connected in such a way that individual’s data can be analyzed at both time points and the amount of improvement between the pre- and post-test measures can be determined. This should indicate how effective our program has been at reaching its goals. The data can also be analyzed at the group level. Advantages of this type of evaluation strategy include low cost and feasibility. Some disadvantages include a risk of maturation bias and history threats. Maturation bias, or a change in outcomes due to participant maturation independent of the program, is a particular concern because as transplant recipients get farther out from their transplant and their skin cancer risk increases, they may naturally become more concerned about skin cancer. History threats could be present if another event occurring between the baseline assessment and the post-test assessment affects the results.

In attempt to reduce the potential for confounding due to maturation, we will do a group level comparison between individuals at various post-transplant years at baseline and individuals at that same point post-transplant during follow-up visits. For instance, we will compare
baseline responses from a group of participants who is one year out from their transplant to follow-up responses from the group that is one year out from their transplant. This group level method will also be employed to assess skin cancer development. Because the risk of skin cancer increases yearly after transplant, a comparison of skin cancer development at baseline and follow-up for a group of individuals is expected to demonstrate higher rates of skin cancer at the post-test assessment. To address this, we will compare baseline skin cancer data for individuals 1-, 3-, 5-, and 10-years from transplant with follow-up data for individuals who are 1-, 3-, 5-, and 10-years from transplant at the time of follow-up.

Clinic processes can also be conducted within a pre-test and post-test framework, allowing program evaluators to determine whether clinic processes have changed over time in conjunction with the SCP Initiative. These assessments could determine aspects of implementation such as how frequently patients are referred to dermatology, how frequently skin cancer prevention is a topic at patient seminars, and how often transplant recipients are risk stratified at dermatology visits.

**Ecological Design**

To provide a second measure of how our program may be affecting skin cancer rates, we will use another quasi-experimental design—an ecological study. Using this design, changes in annual skin cancer rates over time among transplant recipients at UNC will be compared with skin cancer rates among transplant recipients at nearby transplant centers. If the annual rate of skin cancer among transplant recipients at UNC is diminishing faster at UNC than at other institutions or growing more slowly at UNC than at other institutions, this supports a conclusion that the program is effective at reducing skin cancer development. However, this must be interpreted cautiously due to limitations of this design.
**Observational Design Components**

Both of the above designs will include observational components, including focus groups, surveys, open-ended interviews and document review. In addition, an observational design will be used to assess important factors such as program acceptability, success of program implementation, and challenges faced during implementation. An observational design will also be used to identify suggestions for improvement from key stakeholders.

**Evaluation Techniques**

To assess the SCP Initiative, we will collect both qualitative and quantitative data. Qualitative methods include open-ended interviews, surveys, and document review. Quantitative analytical methods include assessment of skin cancer rates based on medical chart review and rates of process measures such as dermatology referral and risk assessment as determined by program records.

Evaluators will conduct open-ended interviews and focus groups with transplant recipients, transplant clinic staff, and dermatology clinic staff. These interviews and focus groups will assess acceptability of the program to key stakeholders, experiences with the program, barriers to fully implementing the program, and areas for program improvement. Evaluators will also conduct surveys of each of these groups to determine how effective the program has been at improving clinic processes and knowledge of participants and clinic staff.

Review of program documents will be a key means of determining efficiency of program processes. This will allow evaluators to determine measures such as how frequently dermatology referrals and risk assessment are completed and how frequently transplant recipients attend clinic visits. Finally, medical record review will be used to determine skin cancer incidence among transplant recipients both before and after program implementation.
Evaluation Planning Tables

Short-Term Objective 1: (Process Objective)

By month six, 100% of transplant coordinators at participating transplant clinics will have received a set of tailored recommendations for how their clinic can help patients reduce their risk of skin cancer along with contact information for a project coordinator. This will include published, evidence-based guidelines where possible, as well as a tailored plan designed through collaboration between the transplant clinics and dermatology department based on best available evidence and feasibility.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did each transplant coordinator receive a tailored set of recommendations within six months of the program start?</td>
<td>Program Coordinator</td>
<td>Review of documents: emails, meeting notes</td>
</tr>
<tr>
<td>Were relevant guidelines and evidence-based practices for skin cancer prevention in transplant recipients identified?</td>
<td>Program Coordinator and Dermatology Faculty</td>
<td>Document review: evidence summary based on Program Coordinator literature review, recently published review articles in the field</td>
</tr>
<tr>
<td>When the evidence was not clear, were dermatologist recommendations followed?</td>
<td>Dermatology Faculty</td>
<td>Open-ended interviews Document review: tailored recommendations</td>
</tr>
<tr>
<td>What program approaches may be most feasible for implantation in each participating clinic?</td>
<td>Program Coordinator and Transplant Coordinators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>Did any transplant clinics decline to participate? Why?</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>Was the final set of recommendations for</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews Document review: tailored recommendations</td>
</tr>
</tbody>
</table>

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Was open communication throughout the process achieved?

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By month 18, what percentage of patients added to the wait list at participating transplant clinics seen at UNC dermatology clinic within 6 months of being added to the wait list?</td>
<td>Transplant Coordinators, Dermatology Clinic Staff</td>
<td>Document review: transplant clinic waitlists, chart review, dermatology clinic calendars</td>
</tr>
<tr>
<td>Were there any barriers to achieving this objective?</td>
<td>Transplant Coordinators, Dermatology Clinic Staff, Transplant Recipients</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
<tr>
<td>Was dermatology referral included in key checklists at each clinic?</td>
<td>Transplant Coordinators, Program Coordinator</td>
<td>Open-ended interviews, Document review: key checklists</td>
</tr>
<tr>
<td>What challenges have dermatology clinic staff experienced with seeing these transplant recipients?</td>
<td>Dermatology Clinic Staff</td>
<td>Open-ended interviews, focus groups</td>
</tr>
</tbody>
</table>

Short-Term Objective 3: (Process Objective)

By month 18, 100% of patients who have been seen by dermatology will have their skin cancer risk level documented in their medical record.
### Evaluation Questions

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By month 18, what percentage of transplant recipients seen by dermatology had their skin cancer risk level documented in their medical record?</td>
<td>Dermatology Clinic Staff</td>
<td>Document review: list of transplant recipients, medical chart review</td>
</tr>
<tr>
<td>Is the dermatology clinic’s system for flagging waitlist and post-transplant recipients at check-in effective?</td>
<td>Dermatology Clinic Staff (check-in staff)</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
<tr>
<td>Is the risk assessment tool easy to use? Is there a way to make it more straightforward?</td>
<td>Dermatology Clinic Staff (physicians and residents)</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
<tr>
<td>Is an appropriate system in place to remind physicians and residents to record the risk level in medical records?</td>
<td>Dermatology Clinic Staff (physicians and residents)</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
<tr>
<td>Are physicians using the transplant patient template in the electronic medical record system? Could it be improved?</td>
<td>Dermatology Clinic Staff (physicians and residents)</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
</tbody>
</table>

### Short-Term Objective 4: (Process Objective)

By year two, patients at participating transplant clinics will attend 75% of recommended dermatology visits.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 2, what percentage of recommended dermatology visits are attended by patients at participating transplant clinics?</td>
<td>Dermatology Clinic Staff</td>
<td>Document review: transplant clinic patient lists, dermatology clinic transplant recipient list, medical chart review</td>
</tr>
<tr>
<td>What barriers are in place to prevent patients from</td>
<td>Transplant Recipients, Transplant</td>
<td>Open-ended interviews, Focus groups, Surveys</td>
</tr>
<tr>
<td>Question</td>
<td>Participant</td>
<td>Evaluation Method</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Do transplant recipients at participating clinics feel that attending dermatology clinic visits is important?</td>
<td>Transplant Recipients</td>
<td>Surveys</td>
</tr>
</tbody>
</table>

**Short-Term Objective 5: (Outcome Objective)**

By year two, 80% of light-skinned patients at participating clinics who are more than 12 months out from their transplant will be able to report that they are at higher risk for skin cancer than the general public, identify skin cancer as the reason extra sun protective measures are encouraged, and name at least three steps they can take to reduce their risk of developing advanced skin cancer.
<table>
<thead>
<tr>
<th>Question</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are educational materials accessible (available, appropriate reading level) to patients?</td>
<td>Transplant Recipients</td>
<td>Focus groups, Baseline and Follow-up Surveys</td>
</tr>
<tr>
<td>Are transplant clinic staff members well educated about skin cancer risk and prevention for transplant recipients?</td>
<td>Transplant Clinic Staff</td>
<td>Surveys, Open-ended interviews</td>
</tr>
<tr>
<td>How can educational efforts be improved?</td>
<td>Transplant Clinic Staff, Transplant Recipients</td>
<td>Open-ended interviews, Focus Groups, Surveys</td>
</tr>
<tr>
<td>Are skin cancer prevention topics being regularly included in seminars and mailings provided to transplant recipients from the transplant clinics?</td>
<td>Transplant Clinic Staff</td>
<td>Open-ended interviews, Document review: newsletters, seminar schedules</td>
</tr>
</tbody>
</table>

**Short-Term Objective 6: (Outcome Objective)**

By year two, 60% of light-skinned patients at participating clinics who are more than 12 months out from their transplant will report that they conduct total body skin self-examinations at least 6 times per year.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 2, what percentage of light-skinned patients at participating clinics who are more than 12 months out from their transplant report they conduct total body skin self-examinations at least 6 times per year?</td>
<td>Transplant Recipients</td>
<td>Survey</td>
</tr>
<tr>
<td>How could skin self-examination education be improved?</td>
<td>Transplant Recipients, Transplant Coordinators</td>
<td>Open-ended interviews, Focus groups, Surveys</td>
</tr>
</tbody>
</table>
**Long-Term Objective 1:** (Outcome Objective)

By year 3, all transplant clinics at UNC will use this program or a modified version of this program that includes regular and adequate education as well as an adequately regular and streamlined process for referring to dermatology.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do all transplant clinics at UNC use this program or a modified version of this program including adequate and regular education and a streamlined dermatology referral process?</td>
<td>Transplant Coordinators</td>
<td>Document review: program documentation, Open-ended interviews</td>
</tr>
<tr>
<td>If any clinics are not using this program or a modified version of it, why not?</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>What challenges have transplant clinics faced in implementing this program?</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews, Focus groups</td>
</tr>
<tr>
<td>If some clinics are using a modified version, how and why did they choose to modify it?</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews</td>
</tr>
<tr>
<td>Is the program continuing to serve the needs of the transplant clinics?</td>
<td>Transplant Coordinators</td>
<td>Open-ended interviews, Focus groups, Surveys</td>
</tr>
</tbody>
</table>

**Long-Term Objective 2:** (Process Objective)

By year 3, communication will be established between UNC Dermatology and dermatology clinics across the state of North Carolina so that transplant patients can be followed by a dermatologist in their hometown if they prefer but tenets of the SCPI are still promoted at their clinic and UNC Dermatology remains a safety net.
### Evaluation Questions

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 3, has communication been established between UNC Dermatology and dermatology clinics across the state of North Carolina?</td>
<td>Dermatology Clinic Staff</td>
<td>Document review: program records, correspondence</td>
</tr>
<tr>
<td>Is a list of dermatology clinics interested in caring for transplant patients compiled and readily available for reference during clinic appointments?</td>
<td>Dermatology Clinic Staff</td>
<td>Document review: program records Open-ended interviews</td>
</tr>
<tr>
<td>Do collaborating clinics throughout the state know what the program entails and that UNC has a high-risk clinic available if their transplant recipients begin to develop multiple cancers?</td>
<td>Participating Dermatology Clinics Throughout the State</td>
<td>Surveys</td>
</tr>
<tr>
<td>What were the greatest challenges in establishing communication with other dermatology clinics and how could this process be improved?</td>
<td>Dermatology Clinic Staff</td>
<td>Open-ended surveys, Document review: program records</td>
</tr>
</tbody>
</table>

### Long-Term Objective 3: (Outcome Objective)

By year 5, obtain free or discounted sunscreen and hats for at least 75% of light-skinned transplant patients at participating clinics.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 5, have free or discounted sunscreen and hats been obtained for at least 75% of</td>
<td>Dermatology Clinic Staff</td>
<td>Document review: program records</td>
</tr>
<tr>
<td>Question</td>
<td>Responsible Party</td>
<td>Evidence</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>light-skinned transplant recipients at participating clinics?</td>
<td>Program Coordinator</td>
<td>Document review: meeting notes, calendar, emails</td>
</tr>
<tr>
<td>Has program staff met with Blue Cross Blue Shield about sunscreen and hat coverage?</td>
<td>Program Coordinator</td>
<td>Document review: meeting notes, calendar, emails</td>
</tr>
<tr>
<td>Have hat manufacturers been contacted about providing free or discounted hats for all transplant patients on a one time basis?</td>
<td>Program Coordinator</td>
<td>Document review: program record, emails, letter drafts</td>
</tr>
<tr>
<td>Have sunscreen manufacturers been contacted about providing free or discounted sunscreens for all transplant patients on a one time basis?</td>
<td>Program Coordinator</td>
<td>Document review: program record, emails, letter drafts</td>
</tr>
<tr>
<td>Have businesses been contacted about donating a percentage of proceeds from a certain item towards providing sunscreen and hats for transplant patients?</td>
<td>Program Coordinator</td>
<td>Document review: program record, emails, letter drafts</td>
</tr>
<tr>
<td>Have program staff identified and regularly applied for grants that could provide funding to purchase hats and sunscreen for transplant patients?</td>
<td>Program Coordinator</td>
<td>Document review: program record, emails, grant proposals</td>
</tr>
<tr>
<td>Is the system of distribution of sunscreen and hats functional for the dermatology clinic and transplant patients? How could it be improved?</td>
<td>Dermatology Clinic Staff, Transplant Recipients</td>
<td>Open-ended interviews, focus groups, Surveys</td>
</tr>
</tbody>
</table>
Long-Term Objective 4: (Outcome Objective)

By year 5, 40% of Caucasian transplant recipients will report always wearing a wide brim hat for outdoor activities and 60% of Caucasian transplant recipients will report applying adequately high SPF sunscreen at least 5 days per week year round prior to going outside.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 5, what percentage of light-skinned transplant recipients report always wearing a wide brim hat for outdoor activities?</td>
<td>Transplant Recipients</td>
<td>Surveys</td>
</tr>
<tr>
<td>By year 5, what percentage of light-skinned transplant recipients report using adequately high SPF sunscreen at least 5 days per week year round prior to going outside?</td>
<td>Transplant Recipients</td>
<td>Surveys</td>
</tr>
<tr>
<td>Are patient family and friends successfully being incorporated into educational efforts?</td>
<td>Transplant Recipients, Family and Friends of Transplant Recipients</td>
<td>Open-ended interviews, Focus groups, Surveys</td>
</tr>
<tr>
<td>How could the program improve efforts to promote consistent use of hats and sunscreen among transplant recipients?</td>
<td>Transplant Recipients</td>
<td>Open-ended interviews, Focus groups, Surveys</td>
</tr>
</tbody>
</table>

Long-Term Objective 5: (Outcome Objective)

By year 5, a 20% reduction in invasive skin cancers will be observed among UNC transplant patients.

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Participant</th>
<th>Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>By year 5, has a reduction in invasive skin cancers been observed among UNC transplant</td>
<td>Transplant Clinic Staff, Dermatology Clinic Staff</td>
<td>Document review: transplant patient lists, electronic medical records</td>
</tr>
</tbody>
</table>
We will communicate evaluation results in several ways to ensure that stakeholders and other interested groups have the opportunity to learn from the findings. Evaluation findings will be communicated with program staff throughout the evaluation process by using presentations and regular progress reports. This will allow the Initiative to address identified areas for improvement as an iterative process and also ensure that evaluators continue to have all useful input for conducting a comprehensive and valuable evaluation. At the end of the evaluation, we will produce a full, formal written report of the methods, results, and recommendations. This will be disseminated to project staff, dermatology and transplant clinic staff, and funders. To make the results and recommendations more accessible to these individuals, we will also use to present the findings at meetings for the various clinics.

We will also share the results of the evaluation and recommendations with individuals not affiliated with the program, including both interested community or hospital groups and other dermatology and transplant clinics. Information will be shared with community or hospital groups by presenting highlights of the most important findings at existing meetings and by creating a concise handout with an overview of the program and evaluation results. The results and recommendations will be shared with other transplant and dermatology clinics by publishing a summary of the process and findings and by presenting at key national meetings for dermatologic and transplant societies. By disseminating this information more widely, we hope to (a) create a guide for other clinics wishing to implement or modify a skin cancer prevention
program for transplant recipients and (b) help these programs achieve success by outlining the successes, challenges, and failures of the SCP Initiative.
V. DISCUSSION

The development of skin cancer after organ transplantation is a growing problem due to increasing frequency of transplantation and improved survival after transplant\(^1,2\). The prevalence\(^3,6\) and invasive nature\(^11,14\) of NMSC in transplant recipients constitute a substantial burden of suffering in this population, while management of these cancers incurs significant cost to transplant recipients and society\(^43\).

Sun exposure, a primary risk factor for the development of NMSC after transplant, is modifiable. Additionally, early detection through skin examination offers the possibility of removing skin cancers before they become invasive or require more aggressive therapies. As a result, education and prevention efforts targeted towards transplant recipients could substantially reduce the burden of suffering due to skin cancer in this population. Nonetheless, surveys have repeatedly demonstrated deficits in transplant recipients’ knowledge of skin cancer risk and prevention\(^22,23\) and UNC transplant clinic staff report poor transplant recipient attendance at recommended dermatology visits.

The Skin Cancer Prevention Initiative, a program founded in behavioral change theory and modeled from previously successful skin cancer prevention programs, seeks to address an unfilled need for a collaborative and comprehensive skin cancer prevention program for UNC transplant recipients. The primary goal of the program is to reduce the negative effect of skin cancer on quality of life and mortality for these individuals. Key components of the program include developing a streamlined dermatology referral process, identifying individuals at the highest risk of skin cancer, and providing high quality skin cancer prevention education to transplant recipients through multiple sources. Previous research suggests transplant recipients do not effectively absorb information about skin cancer risk for the first year after transplant\(^32\).
and the risk of sun damage is theoretically highest immediately after transplant, during the period of greatest immunosuppression. Because of this, the SCP Initiative begins skin cancer prevention education while future transplant recipients are on the waitlist. Additionally, the program attempts to reduce barriers to using sun protective behaviors by providing free hats and sunscreen to transplant recipients and by educating family members and close friends.

The literature review of similar programs identified five skin cancer prevention programs that showed some promise of increasing use of sun protective behaviors or reducing the risk of skin cancer among the target population. Because each program consisted of multiple components and evaluations assessed the programs as a whole, the value of individual program components could not be determined. As a result, the SCP Initiative combines as many components as possible of each program while maintaining a relatively low budget and administrative burden due to incorporation of the program into existing clinic structures.

A primary weakness of most of the reviewed programs was that the evaluation focused on short-term reported behavior change rather than more meaningful outcomes such as long-term behavior change or development of invasive skin cancer. The evaluation plan for the SCP Initiative addresses a full range of outcomes from barriers to program implementation to development of skin cancer among participants at five years. A full evaluation of the program offers the opportunity to advise others about what aspects of the program were successful and how similar programs could be implemented at other institutions. It would also provide some of the first data regarding the effect of skin cancer prevention programs on skin cancer outcomes in transplant recipients. If the evaluation ultimately demonstrates success at reducing the burden of skin cancer in this population, it would likely aid UNC and other institutions in obtaining funding for further transplant recipient skin cancer prevention efforts.
Although the SCP Initiative is promising, its success hinges on several factors. Without continued support from UNC’s transplant clinics and Department of Dermatology, the program could not be sustained. Because the individuals in these departments who currently support the effort also have numerous other commitments, it will be important to ensure that some program staff have dedicated time to devote to program coordination and improvement. Overall, the program should require relatively little time and effort for the health care providers who will be tasked with educating patients, conducting risk assessments, and maintaining the referral system. As a result, several key components of the program should be easy to implement and sustain. Nonetheless, obtaining grant support and establishing collaborations with insurance companies or sunscreen manufacturers could require substantial effort, as would full-scale evaluation.

As the Initiative is primarily student-led at this time, a significant potential barrier to full-scale program implementation and evaluation is whether grant support can be readily obtained. Grant support will be needed to support additional program staffing, and it would be difficult or impossible to conduct the program evaluation without sufficient funding. Failure to conduct an evaluation would limit contributions to the greater body of knowledge about skin cancer prevention in transplant recipients and limit dissemination of the program to other institutions, even if the program is highly successful. Additionally, a lack of evaluation would be a barrier to quality improvement efforts. Continued quality improvement within the program will be important to ensure program acceptability to all stakeholders and make the program maximally effective. Nonetheless, even if funding cannot be obtained, a partial version of the program that excludes full-scale evaluation and the provision of free hats and sunscreen may still do a great deal to meet the needs of UNC’s transplant recipient population.
VI. ACKNOWLEDGEMENTS

I would like to thank the following people for their contributions, without which I could not have completed this Master’s Paper or begun to envision the Skin Cancer Prevention Initiative.

Diane Calleson, PhD
Brad Merritt, MD
Puneet Jolly, MD, PhD
Carrie Frueauf, BSN, RN, CCTC
Anthony Viera, MD

Your tremendous help and guidance through this process has been invaluable.
Thank you so much!
VII. References


## VIII. Appendix A: Summary of Systematic Review Studies

<table>
<thead>
<tr>
<th>Program and Goal</th>
<th>Target Population</th>
<th>Program Description</th>
<th>Evaluation Strategy</th>
<th>Results</th>
<th>Strengths and Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Project SUNWISE</strong>&lt;sup&gt;25&lt;/sup&gt;</td>
<td>US Postal Workers* in Southern California n=2662 (~ were half controls)</td>
<td>Multi-pronged approach including: - Free sunscreen - Free wide brim hats - Cues to action (keychains, water bottles, and posters with sun safety messages) - Educational presentations (elevated risk of skin cancer, sun protective behaviors, case report of a postal worker with a precancerous growth removed)</td>
<td><strong>Comparison group:</strong> Delayed intervention group of post offices <strong>Methods:</strong> - Surveys of how often each individual used sunscreen and wide brim hats at 3 months, 1 year, and 2 years - Validation by direct observation and measuring sunscreen removed from communal pump bottles</td>
<td>At 2 years, intervention group participants were twice as likely to report always using sunscreen and 2.88 times as likely to report using wide brim hats In the intervention group, “all the time” sunscreen use increased from 27% to 39% over 2 years and use of wide brim hats increased from 27% to 40%</td>
<td><strong>Strengths:</strong> - Long follow-up - Multi-pronged approach - Validation of self-reported measures <strong>Weaknesses:</strong> - No information about impact on skin cancer rates - Cannot identify effect of individual components</td>
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</table>

*population at high risk of skin cancer due to occupational exposure
<table>
<thead>
<tr>
<th>Program and Goal</th>
<th>Target Population</th>
<th>Program Description</th>
<th>Evaluation Strategy</th>
<th>Results</th>
<th>Strengths and Weaknesses</th>
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</table>
| Sunscreen in Transplant Patients<sup>21</sup> | 120 organ transplant recipients (40 kidney, 40 liver, 40 heart) in Berlin, Germany | - Free sunscreen SPF >50  
- Training in proper sunscreen application  
- Completed sunscreen use diaries | **Comparison group:**  
Controls matched on 6 different factors (age, sex, time since transplant, organ transplanted, previous post-transplant malignancies or actinic keratoses)  
**Evaluation:**  
- At baseline and 24 months, counted number of actinic keratoses, SCCs, and BCCS on areas of skin receiving daily sunscreen application  
- Sunscreen use diaries in intervention group  
- Validate reported sunscreen use with number of sunscreen bottles distributed | Intervention group applied sunscreen an average of 5.6 times per week year round  
After 24 months, the control group had 82 new actinic keratoses and had developed 8 SCCs and 9 BCCs.  
The intervention group had regression of 102 actinic keratoses and had developed no SCCs and 2 BCCs.  
The difference in actinic keratoses and SCCs between the two groups were statistically significant. | **Strengths:**  
- Substantial reduction in most important outcomes of interest (development of cancer and precancer)  
- Identified a favorable sunscreen formulation through formative research  
**Weaknesses:**  
- Limited data showing comparability of groups  
- Unclear what portion of the program (free sunscreen, desirable sunscreen formulation, sunscreen application training, or diary) was effective |
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<tr>
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<th>Evaluation Strategy</th>
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| Specialist Dermatology Clinics<sup>27</sup> | White renal transplant patients under follow-up at a United Kingdom clinic between August 2004 and April 2005. 73% of those invited participated. (n=399) | - Detailed history and exam by dermatologist  
- Individualized risk of skin cancer  
- Counseling on sun protective measures | **Comparison group:**  
Individuals who reported they had never been to the specialist dermatology clinic  
**Evaluation:**  
- Survey (dermatology clinic attendance, where received sun protection advise, nature of advice, sun protective measures used, why in need of extra sun protection)  
- Survey results combined with medical record data on time since transplant and history of skin cancer | 89% of respondents had attended the clinic at least once. They had statistically significantly higher knowledge of skin cancer risk and use of sun protective behaviors.  
11% of survey respondents were non-attenders. They were statistically significantly different from attenders with regards to skin cancer history (no previous cancers) and shorter time since transplant. | **Strengths:**  
- Individualized risk assessment  
**Weaknesses*:**  
- Extremely high potential for confounding due to significant differences between attenders and non-attenders  
- 27% survey non-response  
*This is the only program reviewed that had a low quality evaluation, calling into question the validity of the results. |
<table>
<thead>
<tr>
<th>Program and Goal</th>
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</tr>
</thead>
</table>
| **Intensive vs Standard Education**<sup>28</sup>                                | Organ transplant recipients at the Mayo Clinic in Minnesota. (n=202, including 101 intensive education participants and 101 controls)      | - Packets of educational pamphlets at 2, 6, and 9 months after a standard clinic visit | **Comparison group:** 101 patients randomly assigned to control group                | At baseline, the intervention group reported more sun protective behaviors and higher intent to increase sun protection. Intervention group had higher increase in reported sun protection at 3 and 10 months. Control group had larger increases in SSE at 10 months. Substantial gap between knowledge and sun protective behaviors in both groups. *all differences were statistically significant | **Strengths:** - Incorporated multiple theoretical model concepts - Randomization of participants - Assessment of both knowledge and behavior - Evaluation at multiple time points  
**Weaknesses:** - Baseline differences in sun protection and intent to use additional sun protection between groups introduces potential for confounding. - No validation of self-report. |
<table>
<thead>
<tr>
<th>Program and Goal</th>
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<th>Program Description</th>
<th>Evaluation Strategy</th>
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</tr>
</thead>
</table>
| Project SCAPE<sup>20</sup> | Adults in Honolulu, HI, and Long Island, NY, at moderate to high risk of skin cancer. 1371 individuals identified as eligible but only 724 completed baseline survey (n=724, 360 received intervention, and 364 were controls) | **Intervention group:**  
- Individual risk assessment using brief skin cancer risk assessment tool  
- Three packages sent in mail at 2-week intervals: UV self-monitoring aids, instructions for SSE, and information about skin cancer prevention and detection  
**Control group:**  
- Single mailing with standard sun safety booklet, tip sheet on sunscreen use, and bookmark encouraging SSE | **Comparison group:**  
364 individuals randomized to control group  
**Evaluation:**  
- Sun habits survey (knowledge, sun exposure, sun protective behaviors, and SSE behavior) at baseline and follow-up  
- Sun exposure diary (2 weekdays and 2 weekend days)  
- Telephone interviews (sun exposure and sun protective behaviors in previous week) at follow-up  
*Timing of follow-up not addressed in article | Groups were comparable at baseline (no significant differences)  
Increase in sun protective behaviors and SSE in both groups (statistically significant).  
Reduction in sunburns and overall sun exposure in both groups (statistically significant).  
Greater (statistically significant) increase in sun protective behaviors and SSE in tailored group. | **Strengths:**  
- Inclusion of people from geographically distinct locations  
- Large number of participants  
- Low cost per person  
- Multiple evaluation methods  
**Weaknesses:**  
- Low participation out of those eligible  
- No information about timing of follow-up evaluations  
- Cannot identify which components were effective  
- Evaluation based on self-report only |
<table>
<thead>
<tr>
<th>Program and Goal</th>
<th>Target Population</th>
<th>Program Description</th>
<th>Evaluation Strategy</th>
<th>Results</th>
<th>Strengths and Weaknesses</th>
</tr>
</thead>
</table>
| **REACT Skin Self-Examinations**<sup>31</sup> | Renal transplant recipients not under the care of a dermatologist and without any history of skin cancer. Must have undergone transplant between 1 and 1.2 or 3 and 7 years prior to the study. (n=75, 38 received intervention, 37 were in control group) | **REACT workbook included:**  
- Mnemonic for SCC detection  
- Increased risk of skin cancer due to immunosuppressants  
- Importance of early detection of SCC  
- How to identify actinic keratoses  
- Worksheet to evaluate personal sun exposure  
- Assessment of personal SCC risk  
- Actions to take if suspicious lesions noted | **Comparison group:** 37 individuals randomized to control group  
**Evaluation:**  
- Pre-intervention survey to both groups (sun exposure history, knowledge, cancer concerns, attitude toward SSE, self-efficacy for recognizing SCC, SSE behaviors, and likelihood of asking partners for assistance)  
- Repeated survey for intervention group after viewing workbook  
- Follow-up telephone interview at one month for both groups | At baseline, groups similar but with differences in age and attitudes towards SSE. Repeat survey for intervention group found statistically significant increase in knowledge and attitudes favoring SSE. ~3/4 who viewed workbook reported they were very likely to start SSE. At 1 month, 89% of intervention group and 22% of control group reported checking skin since visit. 35% of intervention group participants who had conducted SSE since then found areas of concern compared to | **Strengths:**  
- Workbook development used high quality methods  
- Similar comparison group  
- Measured knowledge and attitudes  
- Measure at multiple time points  
- High participation rate  
- Identification of suspicious lesions **Weaknesses:**  
- Baseline age and attitude differences and lack of repeat survey in control group may confound results |
0% in the control group.
Rate of SSE was comparable between group 1-1.2 and 3-7 years from transplant.
Group who underwent transplant 3-7 years before found statistically significantly more suspicious areas during SSE.

<table>
<thead>
<tr>
<th>Baseline differences in recent SSE may confound results</th>
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</table>
IX. Appendix B: Budget.

<table>
<thead>
<tr>
<th>SCPI 5-Year Budget</th>
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</thead>
</table>

**PERSONNEL**

<table>
<thead>
<tr>
<th>NAME</th>
<th>TITLE</th>
<th>APPT TYPE</th>
<th>EFFORT</th>
<th>DURATION</th>
<th>BASE</th>
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<tbody>
<tr>
<td>TBD</td>
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<td>1</td>
<td>5</td>
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<td>TBD</td>
<td>Coordinator</td>
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<td>TBD</td>
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**SUPPLIES**

<table>
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<tr>
<th>Supplies</th>
<th>TOTAL</th>
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</thead>
<tbody>
<tr>
<td>Brochures and Educational Materials</td>
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</tr>
<tr>
<td>Stamps</td>
<td>$7,500</td>
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<tr>
<td>Misc Printing and Office Supplies</td>
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**DISCRETIONARY**

<table>
<thead>
<tr>
<th>Discretionary</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unanticipated needs</td>
<td>$25,000</td>
</tr>
</tbody>
</table>

**TOTAL 5-YR PROGRAM COSTS** | $164,650
X. Appendix C. Ethical Considerations for the Institutional Review Board Application

In considering the ethics for evaluation of the SCP Initiative, several points must be addressed. Understanding and minimizing the risk for human subjects involved in the evaluation is paramount. The evaluation for the SCP Initiative will involve medical chart review as well as conducting surveys, open-ended interviews, and focus groups with patients. These activities carry minimal risk to the participants as there is no potential for physical harm in this collection of observational data and we will not be asking questions about sensitive subjects.

Confidentiality is also extremely important, particularly since evaluators will view patients’ medical records to determine rates of skin cancer development. If any medical information was inadvertently exposed to individuals other than the evaluators, that would put the individual at risk and be a breach of confidentiality. To address confidentiality concerns, we will de-identify all data at the time that it is recorded to minimize any risk that the individual’s information, should it inadvertently become available to someone other than the evaluator(s), could not be linked to that individual. When seeking focus group and interview participants, we will use guidelines outlined in HIPAA to avoid sharing Personal Health Information with unauthorized individuals while contacting (potential) participants over the phone or through mailings. Additionally, all evaluators will receive HIPAA authorization.

With the exception of the medical chart review, which does not require contacting the individuals, all participants will review and sign an informed consent document before participating. This will need to be written at an appropriate reading level for our target population. This will include a clear and complete description of the study, a description of foreseeable potential risks or benefits, and a statement of the extent to which confidentiality of the records will be maintained.
In summary, we will take care to collect only the information needed for evaluation purposes, we will de-identify data at the time it is collected, and we will use a clear and complete informed consent process. Due to the nature of the evaluation, there will be very minimal risk of any physical, emotional, or other type of harm. Based on this, we will apply for an expedited IRB review.