TAKERS:
An Interactive Online Module to Improve Health Outcomes in Pediatric Chronic Kidney Disease Patients

By

N'Djamina A. Johnson

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Advisor

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Second Reader

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N'Djamina Johnson
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Abstract

Over 15% of children in the United States and 17.2% of children in North Carolina have special health care needs. These children and adolescents (youth) need assistance with transitioning from family-centered pediatric care to independent adult medical care; however, in 2009 less than half of them received the services they needed for a successful transition. Health care transition is vital to decreasing the morbidity and mortality of youth with chronic diseases. The University of North Carolina (UNC) Kidney Center is currently working to expand its health care transition preparation services for youth to meet these needs by developing the TAKERS online module. TAKERS is an acronym for Take your Meds, Ask questions, Know your condition, Eat healthy, Read labels and Seek support.

The goal of TAKERS is to help youth ‘take control’ of their chronic kidney disease which will improve their transition from pediatric to adult care and increase their self-efficacy. Several studies of computerized serious games have been shown to increase healthy eating habits, increase nutrition knowledge, increase positive health behaviors, and improve health outcomes. The theoretical framework of TAKERS is based on the Chronic Care Model to address health care needs and the Health Belief Model to address self-efficacy.

TAKERS will include educational components that will teach the key principles of transition through several online activities. Several components have yet to be developed; however, the UNC Computer Science students have created a “Space TAKERS” component of the module, which will be played on the computer. The participants will be evaluated at baseline, after completing TAKERS, and every 6-12 months after completing TAKERS to determine the effect of TAKERS on improvement of transition. The patients involved in this study will likely also be cross-enrolled in the longitudinal study being conducted by Dr. Maria Ferris with measuring TRxANSITION outcomes.
**Introduction**

Over 15% of children in the United States and 17.2% of children in North Carolina have special health care needs (Child and Adolescent Health Measurement Initiative, 2010). Children with special health care needs include those who have mental, physical, emotional or medical conditions that have been diagnosed by a physician. In previous decades, most of these children did not live to see adulthood; however, with the advancement of medical care, they are surviving and becoming active members of society (White, 2012). These children and adolescents now need assistance with transitioning from family-centered pediatric care to independent adult medical care; however, in 2009 less than half of them received the services they needed for a successful transition (CAHMI, 2010; White, 2012).

With this need in mind, the American Academy of Pediatricians, American Academy of Family Physicians and the American College of Physicians – American Society of Internal Medicine (2002) developed a consensus statement with several goals to for physicians who provide care to young adults to improve their transition from pediatric to adult care. This statement advocated several guidelines including identifying core knowledge and skills required to provide health care transition services and involving young adults in the transition process (American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians - American Society of Internal Medicine, 2002). This group of professional organizations published updated recommendations in 2011 which includes an algorithm (Figure 1) to clarify specific steps and strategies to facilitate the transition (American Academy of Pediatrics et al., 2011). Figure 1 includes only Part A of the algorithm. Part B gives a description of each step, and the published article describes each step more thoroughly.
Health care transition is vital to decreasing the morbidity and mortality of adolescents and young adults (youth) with chronic diseases. For patients with transplanted organs, the survival of transplant is one of the most important predictors of patient survival (Shemesh et al., 2010; Watson, 2005). However, non-compliance in adolescents with kidney transplants has
been reported up to 53% (Watson, 2005). In a retrospective cohort study, youth in the transition period with liver transplants also demonstrated decreased compliance (Annunziato et al., 2007). In another retrospective study, youth with Diabetes Mellitus that did not have a structured transition process had higher Hemoglobin A1Cs than those that had a structured transition process (Cadario et al., 2009). Youth with rheumatologic diseases such as Systemic Lupus Erythematosus and Juvenile Idiopathic Arthritis had increased disease activity during transition (Hersh et al., 2009).

The University of North Carolina (UNC) Kidney Center is currently working to expand its health care transition preparation services for youth to meet these needs by developing the TAKERS online module. TAKERS is an acronym for Take your Meds, Ask questions, Know your condition, Eat healthy, Read labels and Seek support. The purpose is to help youth with chronic conditions ‘take control’ of their chronic kidney disease which will allow them to have a better transition from pediatric to adult care.

**Literature Review**

This literature review serves to inform my program planning to increase the efficacy of TAKERS and inform the development of online program elements. Therefore, I sought to answer the following question: does pairing patient education with interactive online or computer games produce positive behavior change and/or improve health outcomes in youth with chronic conditions?

**Search Strategy**

I searched for articles in PubMed using the following search terms: (game OR games OR gaming) AND (youth OR teens OR adolescents OR adolescence OR teen OR child OR children) AND (chronic disease OR chronic diseases OR asthma OR diabetes OR sickle cell) AND (assessment OR evaluation OR impact). The inclusion criteria are listed in Table 1 below.
This search only led me to one article that I could use. Therefore, I changed the limit to include articles published since January 2000, but limited the results to only include randomized trials. This produced 2 more articles. This search also produced systematic reviews and literature reviews of health games and theory that I will use for background information.

I then searched for journals available at UNC that focused on Health Care and Gaming, which led me to a journal called “Games for Health.” I used the same search terms I used in PubMed without any restrictions on time of publication. I did not find any articles about specific games that fit my inclusion criteria, but I did find a systematic review published in 2012 (Rahmani & Boren, 2012). I used the 3 most recent articles on educational games that were reviewed in that paper (Baranowski et al., 2011; Pempek & Calvert, 2009; Peng, 2009).

**Analysis of Health Games (see Table 2: Summary of Health Games)**

“Escape from Diab” and “Nanoswarm: Invasion from Inner Space”

“Escape from Diab” (Diab) and “Nanoswarm: Invasion from Inner Space” (Nano) were two computer games developed for obese 10-12 year old minority children to promote physical activity and healthier food choices (Baranowski et al., 2011). The children were recruited in Houston, Texas via radio station ads targeted at ethnic minorities, particularly parents of African-American and Hispanic children. The inclusion and exclusion criteria mainly ensured that the children were obese, not physically active, did not have medical conditions that would hinder changes in diet, and could speak and understand English.

After recruitment and exclusions, the children were randomized to the treatment group or the control group. There were no statistically significant demographic differences between the

<table>
<thead>
<tr>
<th>Online or computer games</th>
<th>Purpose of intervention is to educate and/or produce positive health behavior change</th>
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<tbody>
<tr>
<td>Target population: children or young adults</td>
<td>Main outcome: effect of intervention on behavior change and/or education retention</td>
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<td>Written in English</td>
<td>Access to article for free via UNC</td>
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**Table 1: Inclusion Criteria for Literature Review**
treatment group and the control group; however there were some differences in diet, BMI and physical activity despite randomization (Baranowski et al., 2011).

The treatment group included 103 children who played Diab, took a test, and then played Nano (Baranowski et al., 2011). Each of the nine 40 minute sessions with Diab and then Nano included attaining mastery in goal setting and anticipatory problem solving. Each session encouraged behavioral change via personalized motivational messages. The goal behavior menu was tailored to dietary or physical activity behaviors of each individual player. The control group included 50 children who were given knowledge-enhancing internet activities (Baranowski et al., 2011). Part 1, called “Good Food and Play Make a Balanced Day,” focused on physical activity, diet and obesity. Part 2, called “Dish it Up,” focused on nutrition.

The blinded data collectors were trained to adhere to very specific procedures for measuring height, weight, and triceps skinfolds (Baranowski et al., 2011). They used standard tools for all measurements such as an accelerometer to measure physical activity levels. Most other outcomes such as 24-hour dietary recall were measured by self-report. Though they did employ a social desirability scale to determine if data may be skewed based on social desirability.

The results showed that the children playing Diab and Nano increased fruit and vegetable consumption by about 0.67 servings per day (p<0.018) but there was not a significant difference in water consumption, moderate-to-vigorous physical activity, or body composition (Baranowski et al., 2011). However, it is important to note that though there was an increase in fruit and vegetable consumption, it was still below minimum daily requirements for children. Also, in children’s and parent’s questionnaires, 80-90% of children said that they enjoyed playing the game.

Overall this was a very well designed and executed study. Each intervention provided some form of educational gaming for the children to help prevent drop-outs or loss-to-follow-up
They also provided increasing monetary incentives for each follow-up (baseline, after Diab, after Nano, and 2 months later). After 153 children were randomized 10 dropped out or were lost to follow up from each group (treatment and control) by the end of the trial; therefore, it is unlikely that selection bias is caused from this attrition. The blinded and trained data collectors, standardized equipment, and strict guidelines on correct measurements minimized measurement bias. Though data that is supplied by self-report may be untrue based on social desirability, the researchers tried to address this by incorporating a social desirability scale which had an alpha of 0.81 at baseline. However, self-reported data is still subject to recall bias, which cannot be full avoided. The researchers controlled the statistical model for potential confounding variables including demographic characteristics, social desirability of response, and duration of game play. Though this study has a small sample size, its design and execution makes it internally valid. The external validity may be limited to minority populations since that was the target enrollment for this study.

This study provided evidence that tailored, interactive, educational computer gaming aimed at improving health of obese minority children may be effective in encouraging healthier food choices, but not very effective in increasing physical activity or causing changes in body composition (Baranowski et al., 2011).

**Pac-Man-type Advergame**

An advergame is a computerized or online game that functions mainly as an advertisement for food products (Pempek & Calvert, 2009). In this study, the researchers developed two variations of an advergame modeled after Pac-Man to evaluate how advergames can affect choices of healthy or unhealthy snack choices in low-income African-American children. This cross-sectional study recruited low-income African American students from 5 metropolitan area elementary schools in Washington, D.C. (Pempek & Calvert, 2009). The study included 15 girls and 15 boys aged 9-10 in the 3rd and 4th grades.
The game developed by the researchers featured a healthy version and an unhealthy version (Pempek & Calvert, 2009). The healthy version awarded points for getting Pac-Man to eat healthy snacks (ex: banana and carrots) and deducted points for eating unhealthy snacks (ex: potato chips and chocolate candy bar). The unhealthy version did exactly the opposite: rewarded unhealthy snacks, and deducted points for healthy snacks. The children were randomized into one of three groups: 1) children played the healthy version of the game then chose a snack, 2) children played the unhealthy version of the game then chose a snack, 3) the control group chose a snack first and then played the healthy version of the game. The snack choices presented to the children before or after game play were identical to the foods pictured in the game for Pac-Man to eat. All 30 students participated with no drop-outs.

This study showed that children who played the healthy version of the advergame selected significantly more healthy snacks than those who played the unhealthy version (Pempek & Calvert, 2009). In the control group, 60% of the students chose at least one healthy snack. There was not a statistically significant difference between the control and the unhealthy or healthy group. Twenty-seven of the 30 children reported that they “really liked” the game, two “liked” it and one did not answer. Nineteen of children reported that the difficulty of the game was “just right,” five said it was easy,” five said it was “hard,” and one child did not answer.

This study is of good to fair quality; however, information is missing to be able to critically appraise it. First, there is no detailed information on the participants to determine any significant differences among the three groups. Also, the researchers did not describe the inclusion or exclusion criteria to appropriately evaluate for selection bias. Though there were no drop-outs and no loss to follow-up, there is not much detail about the selection process in order to fully evaluate for selection bias. Since the exposure was very similar for all 3 groups, the researcher asked the same questions to all students, and all students were only allowed to play for 5
minutes, there is only a low risk for measurement bias. The researchers attempted to control for confounders by getting an equal number of boys and girls, randomizing them into the 3 groups, and having each child play the game twice and chose snacks individually rather than in a group (Pempek & Calvert, 2009).

The internal validity of this study is good even though it is a very small sample size. Their snack choices are likely related to their game play since it was such a controlled environment. However, it is the controlled environment that leads me to doubt the external validity of this study. The average way in which a 9 or 10 year old chooses a snack does not involve the presence of a researcher, game play and answering questions before choosing a snack. Also, this study is targeted toward low-income African American children. Therefore, the results may only be best applied to that demographic group.

This study is an example of how a very short, minimally graphic health game can produce immediate behavior change in low-income African-American children (Pempek & Calvert, 2009). However, it does not provide any long-term data on these choices. It also provides evidence that online food advertising could have a positive or negative effect on children’s food selection.

Right Way Café

The Right Way Café is a computerized game used to promote a healthy diet for young adults (undergraduate students at Michigan State University) by attempting to increase nutrition knowledge, self-efficacy of healthy eating and perceived benefits; while decreasing perceived barriers to healthy eating and trigger the individual’s intentions to be on a healthy diet (Peng, 2009). The 42 participants (32 women) were recruited from 2 large undergraduate classes and then randomized to the treatment group or the control group. The mean age of participants was 20 years old.
The treatment group participated in the Right Way Café, and the control group did not do any intervention (Peng, 2009). The Right Way Café allows the participant to choose a character, and build characteristics into this character that are similar to the participant such as height, weight, and level of physical activity. Based on their inputs, tailored eating information is presented (such as daily caloric intake). The player must then choose food items to eat for the week, at which time immediate feedback is given on the benefits and/or harms of different food choices. At the end of the simulated week, the character will gain or lose weight and receive appropriate feedback about the direction and speed of weight gain or loss to help make better decisions for the next week. The entire game simulates 3 weeks, and took most participants a mean time of 42 minutes to complete.

All participants were given a pre-test, post-test and a 1 month follow-up test (Peng, 2009). The follow-up test had a high attrition rate of 20%. This included 7 individuals from the control group and 1 individual from the intervention group. They tested individuals on their knowledge of the food pyramid and general nutrition knowledge. They also included question items about each participant’s self-efficacy of healthy eating, self-efficacy for veggie and fruit consumption, perceived benefits of healthy eating, and perceived barriers of healthy eating. The players also evaluated the game on a 7-item scale. It is interesting to note that they did not include any questions on actual behavior changes.

The results showed that controlling for the pre-test, nutrition knowledge, the treatment group had a significantly greater score on food pyramid knowledge than the control group at posttest after controlling for the pre-test (p<0.05) (Peng, 2009). However, retention was low, as both groups had a decrease in knowledge at the one month follow up testing. Also, after controlling for the pre-test scores, the treatment group had a significantly higher score in self-efficacy, perceived benefits, and healthy eating intention when compared to the controls.
Contrary to expected results, the perceived barriers for treatment group had a slight increase, and the control group had slight decrease.

The game was evaluated on a scale of 1 to 7 on the following indicators: interesting (mean-M, 5.85 standard deviation - SD 1.18), well designed (M 5.75, SD 1.16), learned something useful (M 6.00, SD 1.26), was a credible source of information (M 5.64, SD 1.24), tailored to individual (M 5.63, SD 0.81), easy to navigate (M 5.64, SD 0.83), and interface was user friendly (M 5.64, SD 0.83) (Peng, 2009). Also, there was a positive correlation between enjoyment of game and several other variables including self-efficacy and healthy eating intention (r=0.59).

Similar to the previous intervention, this study also does not include information on participant characteristics or exclusion/inclusion criteria (Peng, 2009). They also had a high attrition rate though they did try to take this into account by running a series of analyses under different assumptions. In addition, all of their participants were educated young adults (undergraduate students), most of whom were female. All of these factors add to the high risk for selection bias and its external validity is also limited. Though their questionnaires seem to be reliable (low measurement bias) based on their alpha levels above 0.80, the absence questions on behavior changes were left out of the questionnaire—especially on the 1 month follow-up, is a major aspect of this study that is missing.

Overall this study is of fair quality. It is well grounded in Health Behavior Theory, and produced results that are in line with theories suggesting that behavior change will come from this intervention (Peng, 2009). However, more follow-up is needed with further questioning on actual behavior changes that may have resulted from this intervention.

This study showed that a personalized intervention on healthy eating can increase nutrition knowledge and self-efficacy (Peng, 2009).

Watch, Discover, Think, Act
Watch, Discover, Think, Act is an interactive multi-media computer game to enhance self-management skills and thereby improve asthma outcomes in inner city youth in Houston, Texas (Bartholomew et al., 2000). The participants were recruited from four Pediatric clinics that served inner city African-American and Hispanic Youth. The inclusion criteria were age 6-17, moderate to severe asthma, English-speaking, and no chronic disease other than asthma.

The children were randomized to play the game at a pediatricians visit or to control group which was usual care (Bartholomew et al., 2000). After losing 38 children to follow-up, 133 children participated in the study with a mean age of 11.5, 86 males and 47 females. This sample was 45.9% Hispanic, 49.6% African American and 4.6% other race/ethnicity. All of the children’s asthma was classified by child’s physician as moderate to severe.

Watch, Discover, Think, Act was developed after performing a needs assessment based on gaps in pediatric asthma care, especially for inner-city minority children at the time (Bartholomew, Shegog et al., 2000; Bartholomew et al., 2000) After reviewing the literature on health education and promotion, they decided to focus their intervention on reducing hospitalizations, emergency room visits, daytime and nighttime symptoms, and increased school attendance and performance using two categories of behavior change: asthma-specific behaviors (taking meds, removing environmental triggers, etc.) and self-regulatory processes (monitoring behavior and symptoms, comparing with the standard, identifying a problem, trying and evaluating a solution). They decided to use symbolic modeling as a principle method to elicit change in child’s knowledge and skills, self-efficacy, outcome expectations and attributions (Bartholomew, Shegog et al., 2000).

Watch, Discover, Think, Act is an adventure game in which the player makes choices to manage the game character’s asthma in order to improve asthma specific and self-regulatory skills (Bartholomew, Shegog et al., 2000). In the game, the main character could match the participant’s gender and ethnicity (Bartholomew, Gold et al., 2000). Characteristics of
The protagonist’s asthma were tailored to be like those of the participant. An older child serves as a coach to model decision-making. They can play in a “watch and discover” mode to identify symptoms and ensure appropriate preventative care and predict environmental triggers. They then “think” to discover if there is a problem based on symptoms and other cues. They can then “act” to find a solution to the problem, and determine if it was effective.

The baseline information was retrieved from parent or primary care taker and the child during clinic visit of enrollment (Bartholomew, Gold et al., 2000). Parents and children were interviewed about asthma management, knowledge of asthma, etc. with a pre-test and a post-test. For the child, this included measurements of the child self-efficacy, self-management, knowledge of asthma management, and child knowledge of self-regulatory steps. To measure health outcomes, they asked parents about their child’s symptoms over past 3 months using the Usherwood Symptom Questionnaire (baseline alpha 0.93). Hospitalization and Emergency Room visits were also measured via parent report over the past year.

Though there is a large volume of data reported in the results section of this study, the primary summary is that the intervention was associated with fewer hospitalizations, better symptom scores, increased functional status, greater knowledge of asthma management, and better child self-management behavior (Bartholomew, Gold et al., 2000). In the evaluation of the program, they measured implementation, program appeal, and progress evaluation of the children (Bartholomew, Shegog et al., 2000; Bartholomew, Gold et al., 2000). To measure program appeal, they asked the children what they would tell their best friend and other children with asthma about the program. Ninety-seven percent of the children said that they would tell their friends that the game was fun and educational. To measure the progress of child, they recorded it on a scale of 1 to 5 with 1 being “needing assistance” and 5 being “engaging in the game.” Ninety-four percent of children needed assistance getting started with the game and occasionally while playing.
Overall, the quality of this study was good. It was well grounded in theories of behavior change, and was the product of extensive literature review and application of key needs of a population (Bartholomew, Shegog et al., 2000). The characteristics of the population described in Table 1 showed that there were no significant differences between the control group and the intervention group after randomization (Bartholomew, Gold et al., 2000). Selection bias was minimal as attrition did not differ between the groups. The measures via questionnaire had alpha levels above 0.80, which indicated relative reliability and lower measurement bias. However, some recall bias is present since several measures were self-reported or reported by parents such as hospitalizations and emergency room visits in the past year. Also, age may be a confounding factor since certain parts of the post-test were open-ended questions. Many children under 9 had difficulty answering those questions, and there was a positive correlation with age and correct answers for the open ended questions. Internal validity is good in this study since it was well designed and implemented (Bartholomew, Gold et al., 2000). The external validity, however, may be limited due to the minority, low-income population targeted in this intervention.

This study gives strong evidence for the efficacy of interactive health interventions paired with primary care visits in low-income, minority children with asthma. Health outcomes, behavioral outcomes, and knowledge level improved when compared to usual care (Bartholomew, Gold et al., 2000).

Asthma Control

Asthma Control is a computerized multi-media software program that was developed to teach inner city children aged 3 – 12 years old about asthma and its management (Homer et al., 2000). After a 10 month enrollment period at a hospital-based primary care clinic in Boston and an affiliated neighborhood health center, 137 families were consented and randomized to Asthma Control (n=76) or the control group (n=61). Children were eligible if they
were 3 – 12 years old and had outpatient visits, ED visits, and/or inpatient admissions for asthma in the year before enrollment. Children were excluded if they had a second major chronic illness with pulmonary component, resided outside of Boston, or were involved in other trials or protocols related to asthma. According to population characteristics depicted in Table 1, there were no statistically significant difference between the treatment group and the control group.

The treatment group and control group were both instructed to visit the clinic three times (Homer et al., 2000). The treatment group would play Asthma Control during that visit, and the control group would get written educational materials with a research assistant or play a non-educational game. Asthma Control was a graphic display of a child going through simulated daily events. The game focused on monitoring, allergen identification, use of medications, the use of health care services, and maintenance of normal activity. The object of the game is to help the main character, Spacer, who is a superhero with asthma. The child must help Spacer get through 3 home and 3 outdoor activities while keeping his asthma under control. In order to complete the game successfully, the children have to make asthma management decisions that are available in their daily lives like taking rescue medications, pre-medicating before exercise, and avoiding environmental allergens.

The primary outcome, obtained by parent report, was acute health care use, including emergency department and outpatient use (Homer et al., 2000). Secondary outcomes included parental report of asthma symptom severity, child functional status, child’s school absences, satisfaction with care, and parental and child knowledge of asthma. The parents were surveyed monthly by telephone to gather this information. Also, parents and children were assessed before and after each computer game to learn impressions of the computer game and assess their knowledge and understanding of asthma. A researcher also observed the child and parent while playing game to gather other nonverbal clues and offer assistance to the child.
playing the game. Finally, there was an exit questionnaire mailed to all participants 9 months after enrollment.

Both groups showed substantial improvement in all outcomes during the follow-up period (Homer et al., 2000). There were substantial reductions in emergency department and unscheduled office visits for asthma, reported asthma severity, and the impact of asthma on parental personal time in both groups. Parents in both groups also reported improvements in child behavior and use of peak flow meters. There was no significant difference demonstrated between the 2 groups in outcomes except that the group that used Asthma Control had increased asthma knowledge. All of the participants in the Asthma control group stated that they enjoyed playing the program. Parents enjoyed the videos, but children thought that they just interfered with the gaming.

Overall this was a very well designed and executed study. The exclusion and inclusion criteria did not appear to create a selection bias and 80% of control and 75% of treatment group completed the questionnaire at 9 months after the start of the intervention (Homer et al., 2000). There were no significant baseline differences in those who completed the survey and those who did not. Therefore, this selection bias is minimal in this study. Measurement was relatively equal, valid and reliable. However, there were only 61% of enrolled families who returned for more than 1 visit even though they were required to come for three (57% control 63% treatment group). There was no statistically significant difference in the number of visits in each group. As with the other studies, social desirability and recall bias may have an effect on the results as well.

Also, this study recruited most patients at a visit in which they were following up after an exacerbation or were currently dealing with an exacerbation (Homer et al., 2000). This may be part of the reason why both groups had such great improvements in outcomes. Internal validity of this study was good due to the strength of the study design; however, it would have been
better if all of the participants would have responded to the follow-up survey. The external validity may be limited to inner-city children with moderate to severe asthma.

This did not produce results that showed that gaming was more effective than traditional methods of health education (Homer et al., 2000). However, it does show that computerized health education can improve knowledge of asthma, and that health education in general could have an important positive impact on health outcomes in inner city children.

**Discussion**

All of these reviewed studies used program elements that could be applied to TAKERS. First, many of them incorporated personalized components. Diab and Nano provided goal behavior tailored to the diet and physical activity of the participant and personalized motivational messages (Baranowski et al., 2011). Right Way Café allowed the player to personalize their gamer to be more like themselves (Peng, 2009). With TAKERS, a tailored personalization is outside of the expertise of the TAKERS team members; however, TAKERS will allow learners to choose which line of education or questioning fits their educational needs. For example, those suffering from uncontrolled hypertension will be able to choose education about this topic while others can skip it.

Also, Right Way Café offered immediate feedback to the gamer on food choices (Peng, 2009). In one component of the TAKERS module, players will be given immediate feedback on correct and incorrect choices to guide their future answer choices and increase knowledge retention.

Self-efficacy was a topic discussed and tested by several of the trials (Bartholomew, Shegog et al., 2000; Homer et al., 2000; Peng, 2009). Self-efficacy is a key component of the Health Behavior model, the same theory on which TAKERS is based. To ensure validated measures, members of the TAKERS team may contact the authors of these studies for their self-efficacy scales to see if they can be adapted for use with TAKERS self-efficacy evaluation.
The evaluation components of these games were also informative. Though the evaluation focused on enjoyment, the researchers also asked questions about the level of difficulty, ease of navigation, and overall design of the game (Baranowski et al., 2011; Pempek & Calvert, 2009; Peng, 2009). This information will be included in the evaluation component of TAKERS, as it will allow adjustments during the pilot study and before a larger launch.
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<thead>
<tr>
<th>Summary of Intervention</th>
<th>Main Results</th>
<th>Program Evaluation</th>
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<tr>
<td>(Baranowski et al., 2011)</td>
<td>The treatment group played Diab and Nano, which were two computer games developed for obese 10-12 year old minority children to promote physical activity and healthier food choices. The control group was given internet-based educational material on diet and exercise.</td>
<td>Children playing Diab and Nano increased fruit and vegetable consumption by about 0.67 servings per day (p&lt;0.018) but there was not a significant difference in water consumption, moderate-to-vigorous physical activity, or body composition.</td>
</tr>
<tr>
<td>(Pempek &amp; Calvert, 2009)</td>
<td>The researchers developed an advergame modeled after Pac-Man to evaluate how advergames can affect snack choices in low-income African-American children. Group1: healthy game then snack choice Group 2: unhealthy game then snack choice Group 3: control group, snack then healthy game</td>
<td>Ninety percent of healthier game participants chose at least one healthier snack while only 10% chose at least one healthy snack in the unhealthy game (p=0.001). There was no statistically significant difference between control group and either game.</td>
</tr>
<tr>
<td>(Peng, 2009)</td>
<td>The Right Way promoted a healthy diet for young adults (undergraduate students) by attempting to increase nutrition knowledge, increase self-efficacy of healthy eating, trigger the individual’s intentions to be on a healthy diet, increase perceived benefits of healthy eating, and decrease perceived barriers to healthy eating.</td>
<td>The Right Way Café was effective in teaching nutrition and weight management knowledge, increasing self-efficacy, perceived benefits of healthy eating, and intention to be on a healthy diet. Both groups decreased in nutrition knowledge at 1 mo., but the treatment group still had greater self-efficacy.</td>
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<tr>
<td>(Bartholomew, Shegog et al., 2000; Bartholomew et al., 2000)</td>
<td>Watch, Discover, Think, Act is an interactive multi-media computer game to enhance children’s self-management skills with their asthma and thereby improve asthma outcomes in minority, inner city children.</td>
<td>Intervention was associated with fewer hospitalizations, better symptom scores, increased functional status, greater knowledge of asthma management, and better child self-management behavior.</td>
</tr>
<tr>
<td>(Homer et al., 2000)</td>
<td>Asthma Control is a computerized multi-media software program that that was developed to teach inner city children about asthma and its management. It was compared with children who were given written educational materials with a research assistant as the control group.</td>
<td>There were substantial reductions in emergency department and unscheduled office visits for asthma, reported asthma severity, and the impact of asthma on parental personal time in both groups. The only significant difference between the 2 groups is that the group that used Asthma Control had increased asthma knowledge.</td>
</tr>
</tbody>
</table>

Table 2: Summary of Health Games
Overview

Several studies of computerized serious games have shown to increase healthy eating habits, increase nutrition knowledge, increase positive health behaviors, and improve health outcomes (Baranowski et al., 2011; Bartholomew, Shegog et al., 2000; Homer et al., 2000; Peng, 2009; Wang & Chiou, 2011). Several studies have also shown that there are common misunderstandings about chronic kidney disease and that education can improve health outcomes such as better blood pressure control, improved diet adherence, and better management of phosphorus and calcium levels (Li et al., 2011; Lingerfelt & Thornton, 2011; Wright, Wallston, Elasy, Ikizler, & Cavanaugh, 2011). UNC has developed a validated tool to measure transition readiness called the UNC TRANSITION Scale™ (see Appendix). This scale tests patients on several topics including improving adherence health behaviors, knowledge of chronic kidney disease to dietary requirements and medications.

Adherence is the “extent to which a person’s behavior corresponds with the agreed recommendations of a health-care provider in terms of taking medications, following a recommended diet and/or executing lifestyle changes” (Kugler, Maeding, & Russell, 2011). In a systematic review of adherence rates of dialysis patients, rates of adherence to oral medications ranged from 3-80%, with more than half of the studies having non-adherence rates greater than or equal to 50% (Schmid, Hartmann, & Schiffl, 2009). This is particularly important in patients with kidney transplants because rejection leads to deterioration of physical functioning and increased psychological and emotional suffering of patients (Nicholas, Picone, & Selkirk, 2011). Also, fluid retention (from non-adherence to fluid intake recommendations) results in increased morbidity and mortality in dialysis patients (Aliasgharpour, Shomali, Moghaddam, & Faghihzadeh, 2012).

In addition to focusing addressing the need for youth-focused transition services, TAKERS also addresses the need to improve health literacy and self-efficacy of young adults.
Health Literacy is defined as the “cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013). The need for improving health literacy is important because about 20% of individuals in the United States speak a language other than English at home and 1 in 11 individuals have limited English proficiency, which is the ability to speak English less than “very well” (Bailey, Sarkar, Chen, Schillinger, & Wolf, 2012). Results from UNC Kidney Center testing indicated that 65% of patients had difficulty understanding directions on a prescription label. In a study of literacy using nutrition labels, 41% of participants received limited literacy/numeracy scores on the food label test (Weiss et al., 2005).

In several studies, low literacy has been associated with poor self-management in patients with end-stage renal disease and several adverse health outcomes such as increased non-adherence to medications and increased preteen smoking and alcohol use (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013). One study found that those with low literacy were more likely to complicate multi-drug regimens which could lead to non-adherence and unintentional drug misuse (Wolf et al., 2011). An observational study showed that those with limited health literacy were more likely to miss dialysis treatments, use emergency care, and be hospitalized related to their kidney disease (Green et al., 2013).

Increasing self-efficacy is also an important goal since it has been shown to be an important factor in causing positive behavior change, reducing stress, improving quality of and improving health measures such as blood pressure and anemia of those with chronic kidney disease (Glanz, 1997; Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012).

It is with these needs in mind that TAKERS is being developed to improve youths’ transition to adult care, their health literacy (by improving their ability to read nutrition and prescription labels), and their self-efficacy with the hope that these measures will lead to
improved health outcomes for these young adults long term as the aforementioned studies have shown.

**Context**

There are several international, national, state and local goals to improve transition of youth from pediatric to adult medical care. A landmark article published by the World Health Organization brought light to the growing concern of adherence to therapies to improve health outcomes (Sabaté, 2003), which is a key component of transition. Also, the United Nations Convention on the Rights of the Child encouraged participation and influence of children (with appropriate levels of cognitive ability) in the decision-making processes of their families, schools, and health care (Nicholas, Picone, & Selkirk, 2011). Two main components of TAKERS are encouraging adherence to therapy and the involvement of children and young adults in their health care maintenance.

TAKERS is consistent with national goals to improve adolescent health care transition as noted in Healthy People 2020 goals listed in Table 2 (U.S. Department of Health and Human Services, 2012b). The Centers for Disease Control and Prevention also developed a National Action Plan to Improve Health Literacy which outlines seven goals to help develop and disseminate health and safety information that is accurate, accessible, and actionable (U.S. Department of Health and Human Services, 2010). As noted previously, one of TAKERS’ main goals is to improve health literacy (by improving their ability to read nutrition labels and prescription labels) of young adults and their parents.

<table>
<thead>
<tr>
<th>Healthy People 2020 Goals Related to Chronic Kidney Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>CKD–7</td>
</tr>
<tr>
<td>CKD–8</td>
</tr>
<tr>
<td>DH–5</td>
</tr>
</tbody>
</table>

*Table 3: Healthy People 2020 Goals Related to Chronic Kidney Disease* (U.S. Department of Health and Human Services, 2012b).

North Carolina created a document to highlight the importance of cultivating adolescents’ health education (North Carolina Institute of Medicine Task Force on Adolescent Health, 2009).
Locally, there is a website that is a resource for those interested in transition resources that also advocates for the advancement of evidence-based transition practices (Healthcare transition research, n.d.). Dr. Maria Ferris, a pediatric nephrologist at the UNC Kidney Center, is the leading force in this initiative. TAKERS is consistent with both of these initiatives in that it is an educational module aimed at improving transition services.

**Acceptability**

Providers will likely be receptive to TAKERS since it requires very little to no effort on their part. All of the modules are online, so the patients (or parent of patients) may simply come to the physician with questions to be clarified, but will not need further guidance from their provider. The acceptability to program recipients is likely to be high based on survey data from adolescents with chronic diseases (Betz, Redcay, & Tan, 2003; Nicholas, Picone, & Selkirk, 2011). Based on a survey administered to adolescents with a wide variety of chronic diseases, adolescents wanted more information about their condition and more youth-centered transition services (Betz, Redcay, & Tan, 2003). In a survey administered to children and adolescents aged 7 – 18 years old with kidney grafts, adolescents were paradoxically reliant on, but frustrated by parental involvement (Nicholas, Picone, & Selkirk, 2011). TAKERS will allow the participants to fill in their gaps in knowledge, and gain skills that will allow them to be more independent from their parents in caring for their health.

**Financial Resources**

The Renal Research Institute will provide financial resources to fund incentives such as movie tickets, iTunes gift cards, and allow for the use of tablets to complete TAKERS during dialysis. In the long term, the incentives may not be available; therefore, participation may wane. If the program proves successful, grant funding may continue to support TAKERS in order to continue to provide the TAKERS module for free.

**Technical feasibility**
With the help of dieticians, residents, and online resources, I am currently developing the TAKERS question database. Student volunteers that Dr. Diane Pozefsky (UNC Computer Science Professor) recruited in the UNC computer science department are using this as a project for an upper level computer science class at UNC. Several difficulties may arise. Though the product that the computer science students are developing is quite amazing, there are other aspects of TAKERS that will need other developers to produce. This resource has yet to be identified. Also recruitment of participants may take longer than expected. Therefore, if TAKERS starts after the students graduate, and we run into technical difficulties, the students may not be available to help. Drs. Pozefsky and Ferris will provide continuity as the computer science students and I graduate so that TAKERS will continue to improve chronic kidney disease patient outcomes.

**Stakeholders**

The stakeholders for TAKERS are Dr. Maria Ferris, Dr. Diane Pozefsky, primary care physicians, patients, and their parents at UNC Kidney Center. Later, if this project is able to be generalized to other pediatric chronic health conditions, it will apply to all pediatric specialists, pediatricians, patients, and their parents. Dr. Maria Ferris is leading the project, so she is very involved in the development of TAKERS. The patients will be involved in focus groups to participate in the planning. Other stakeholders will be involved in the planning as they provide feedback while the intervention is running.

**Theoretical Framework**

The Chronic Care Model and the Health Belief Model are the theoretical frameworks on which TAKERS is based. In the Chronic Care Model, TAKERS aims to help produce the “informed activated patient/family” as shown in Figure 2. The Health Belief Model is the method by which TAKERS will attempt to cause behavior change in the “informed activated patient/family.” In this model, one’s beliefs about their health problem are vital in determining future actions and the individual must address six key ideas before they will feel prepared to act
TAKERS attempts to improve each category shown in the Health Belief Model (Figure 3), including the "knowledge" in the "modifying factors," all of the "individual beliefs," and "cues to action" to improve health outcomes and encourage behavior change (Champion & Skinner, 2008; Glanz, 1997; Smith et al., 2010).

Figure 2: Chronic Care Model. (Brinkman & Epstein, 2011)

Figure 3: Health Belief Model. (Champion & Skinner, 2008)

Though TAKERS participants will be diagnosed with chronic kidney disease (CKD), they will have different perceptions of their susceptibility to complications from CKD and severity of their CKD (see Figure 3) (Glanz, 1997). Therefore, the module will present information about how common certain complications are in patients with CKD. It will also include an evaluation of their own risk based on their current eating habits, compliance with medications, and other factors that may decrease or increase their risk. TAKERS will include stories of young adults...
who have had negative consequences from non-adherence, and then supply recommendations to avoid specific actions to prevent those consequences.

The beliefs that each participant has about the effectiveness of taking action, such as adherence to medications, is called the perceived benefits (Glanz, 1997). In this part of the module, TAKERS will compare the negative stories of young adults mentioned previously with stories of young adults who have had positive consequences from adhering to dietary and medication requirements. The part of the module will encourage specific actions to gain positive consequences.

With many patients with CKD, there are many perceived barriers, or beliefs about the material and psychological costs of taking action (Thomas-Hawkins & Zazworsky, 2005). TAKERS will present specific strategies to overcome these barriers (Gordon, Prohaska, Gallant, & Siminoff, 2009; Smith et al., 2010). The fifth key concept is incorporating cues to action. TAKERS will include specific strategies to create cues to action for remembering to take medications, drink the appropriate levels of fluids, and adhere to their recommended nutritional recommendations (Gordon, Prohaska, Gallant, & Siminoff, 2009; Smith et al., 2010).

Lastly, the module will aim to improve an individual’s self-efficacy or confidence in one’s ability to take action. In one study, a positive correlation was found between self-care ability and self-efficacy (Bag & Mollaoglu, 2010). In another study, children were empowered to more effectively estimate their phosphate intake and it significantly improved the management of their phosphate levels (Ahlenstiel, Pape, Ehrich, & Kuhlmann, 2010). Some teenagers and young adults with chronic kidney disease still rely on their parents to meet the needs of their chronic kidney disease (Nicholas, Picone, & Selkirk, 2011). However, this module will improve self-efficacy by providing education about their condition, the importance of each step it takes to extend the life of their kidney, and the consequences of action or lack of action. TAKERS will also suggest tips to encourage goal-setting, reinforce information they have learned previously, and provide positive role models of young adults demonstrating the desired behaviors.
**Goals & Objectives**

**Goal:** The goal of TAKERS is to improve the health outcomes of youth with chronic kidney disease by improving their transition from pediatric medical care to adult medical care, improving of the ability to read a food label by patients and their parents, and increasing self-efficacy.

In order to achieve the objectives listed below, all participants will complete the TAKERS curriculum. The effectiveness of the TAKERS module will be evaluated with the tools listed below at baseline, at the completion of TAKERS curriculum, and periodically (approximately every 6 – 12 months) until the end of the study 24 months from initiation.

**Short Term Objectives**

1. After completing TAKERS, all participants will improve their readiness for transition.
   - UNC TRxANSITION Scale™: At least 80% of participants will earn an at least an 8/10.
   - TAKERS pre/post-test: At least 80% of participants will earn at least an 80% on the post-test.
   - STARx Transition Readiness Survey: At least 80% of patients will respond with at least 3 out of 5 on each section of the survey.
   - Morisky 8 General Medication Adherence Scale: At least 80% of participants will have a score of 5 or less.
   - Medical Passport: All participants will have a medical passport. The medical passport survey will demonstrate that they carry and use their medical passport when needed.

2. After completing TAKERS, all participants will improve their ability to read a food label.
• REALM (Rapid Estimate of Adolescent Literacy in Medicine): This will only be used to assess baseline literacy level and to compare performance on the Newest Vital Sign test.

• Newest Vital Sign - a Food Label: At least 70% of patients will improve their ability to read a food label based on the score of at least at least 4.

• Prescription Label Test: Goal to be determined (Assessment not yet created).

3. After completing TAKERS, all participants will increase their level of self-efficacy.

• Health Behavior Survey: Goal to be determined (Validated assessment being requested).

**Long Term Objectives**

As long as patients remain in the TRANSITION database, longitudinal data may be collected on their health outcomes periodically to follow-up on the following long term objectives:

1. Participants will have discussed transitioning from pediatric care to adult care with their health care provider (Child and Adolescent Health Measurement Initiative, 2010; U.S. Department of Health and Human Services, 2012a)

2. Patients will have more positive transition outcomes such as improved knowledge about their condition/diet, self-management skills, carrying their medical passport.

3. Patients will maintain higher scores than baseline on the UNC TRANSITION Scale™ and STARX Transition Readiness Survey among other measures used previously if time allows for the completion of other methods of evaluation.

**Program Implementation**

The goal of TAKERS is to improve health outcomes of pediatric patients with chronic kidney disease by improving their transition from pediatric medical care to adult medical care, improving the ability to read food labels, and increasing self-efficacy. In order to accomplish these objectives, it is necessary for the participants to complete the TAKERS curriculum.
However, first, I must develop TAKERS online module in collaboration with UNC Computer Science Department students and faculty. After IRB approval, recruitment will begin and be ongoing for 24 months. In order to add video, pictures, and qualitative data to TAKERS, I will conduct focus groups and visit dialysis units. As patients are enrolled, the research assistants will create medical passports for the participants so they can keep vital information about their condition on hand. Before they begin TAKERS, participants will take several baseline assessment measures described in the Goals & Objectives section which will be repeated periodically. After completion of TAKERS, research assistants will continue to follow participants for the duration of the study, up to 24 months. In the last year of the program, the research team will analyze the data to determine outcomes of TAKERS. A more detailed timeline is shown in Figure 3.

![Study Design and Timeline](image-url)

**Figure 4:** TAKERS Study Design and Timeline. The Youth & Parent Intervention is the TAKERS module. (Figure provided by Dr. Maria Ferris & Colleagues)
TAKERS will include educational components that will teach the key principles of transition through several online activities. This component has yet to be developed. However, the UNC Computer Science students are creating the Space TAKERS component of the module, which will be played on the computer. This game will include multiple choice questions that will appear first as easy questions. As the player answers more questions correctly, the level of difficulty of questions will increase until the database of questions is exhausted. The answers choices will be asteroids floating around in space. The player must aim a space gun at the correct answer and shoot the answer with accuracy. The player can increase the difficulty of the game by causing the asteroids to move faster and increasing the speed of the ammunition.

The Renal Research Institute has provided funding for this project to purchase tablets and other resources needed to implement this project such as incentives for participants. Dr. Maria Ferris has created the budget for this project, as it is a long term project which will last at least 36 months.
**TAKERS Logic Model**

| Assumptions | 1. Children with chronic diseases need support in transitioning from pediatric care to adult care (White, 2012).  
|             | 2. Children should be involved in the health care transition process (AAP, AAFP, ACA- ASIM, 2002; Betz, Redcay, & Tan, 2003).  
|             | 3. Children and adults have difficulty understanding prescription labels and nutrition labels (Weiss et al., 2005).  
|             | 4. Low numeracy can negatively affect health outcomes (Dewalt, Berkman, Sheridan, Lohr & Pignone, 2004).  
|             | 5. Several computerized games have been shown to improve healthy eating habits, increase nutrition knowledge, improve positive health behaviors, and improve health outcomes in children (Baranowski et al., 2011; Barholomew et al., 2000; Homer et al., 2000; Peng, 2009). |
| Inputs      | **People**  
|             | - Project designers  
|             | - Research Assistants  
|             | - Parents of Participants  
|             | - Participants  
|             | - Game developers  
|             | **Organizational**  
|             | - UNC Kidney Center  
|             | - UNC Dialysis Unit  
|             | - UNC Computer Science Dept.  
|             | **Funding**  
|             | - Renal Research Institute  
|             | **Materials & Resources**  
|             | - Tablets & Laptops  
|             | - Data from patient medical records  
|             | - Data from TRxANSITION Research  
|             | - Incentives (cash, gift cards, and/or food)  
|             | - Stationary |
| Activities  | 1. Develop TAKERS online module and conduct focus groups.  
|             | 2. Create medical passports for all participants as they enroll.  
|             | 3. Participants take baseline assessment measures described in Goals & Objectives, and repeat at them at various intervals.  
|             | 4. Participants will complete TAKERS. |
| Outputs     | 1. Immediately after completing TAKERS, participants will have learned…  
|             | - Skills necessary to improve their self-efficacy.  
|             | - About chronic kidney disease, health insurance, and how to read prescription labels and nutrition labels.  
|             | - Ways their condition may interfere with employment, school, and reproduction.  
|             | - Ways to keep up with their medications and doctor’s appointments  
|             | - How to make healthy food choices, find a new doctor and other support systems |
| Outcomes    | At 6-12 month intervals until end of study at 24 months, participants will maintain higher than baseline scores on the assessments administered at the baseline and after TAKERS demonstrating increased knowledge on all of the outputs listed above. |
| Impacts     | 1. Participants will have discussed transitioning from pediatric care to adult care with their health care provider. (Child and Adolescent Health Measurement Initiative, 2010; U.S. Department of Health and Human Services, 2012a)  
|             | 2. Patients will have more positive transition outcomes such as decreased morbidity and avoidable hospitalizations, increased quality of life and self-management skills.  
|             | 3. Patients will maintain higher scores than baseline on the UNC TRxANSITION Scale™ and STARx Transition Readiness Survey among other measures if time allows for their completion. |

Table 4: TAKERS Logic Model
Figure 5: TAKERS Logic Model Prezi. View this Prezi at http://prezi.com/user/ndjamina and view “TAKERS Logic Model or type in the following URL http://prezi.com/kdrofxqhwzb/takers-logic-model/?kw=view-kdrofxqhwzb&rc=ref-30900957
Rationale and Approach to Evaluation

Rationale for Evaluation

According the Centers for Disease Control and Prevention (CDC), the three main reasons for creating an evaluation plan are for rendering judgment (accountability), facilitating improvements (program development), and knowledge generation (transferability) (Centers for Disease Control and Prevention, 2011). This rationale for creating an evaluation plan also applies to TAKERS. First, evaluating TAKERS will help all stakeholders stay accountable to the goals and plans put forth in the program plan. The evaluation will also help inform those currently developing the program and receiving feedback to improve the program while it is being conducted. The development and implementation of TAKERS will be an iterative process that will require feedback in order to continuously improve its effectiveness. Lastly, this project is likely to be published. Therefore, effectiveness data will be of value in the publication. An ultimate goal of the project is that the lessons learned will be transferable to others who would like to develop similar programs at other institutions.

Another general reason that the evaluation plan will be important is because TAKERS has several different evaluation tools that the researchers plan to employ, and the evaluation plan will help to describe each tool for all those involved. It will encourage transparency with participants and stakeholders.

It is with these evaluation goals in mind, that I decided that it will be necessary to perform two types of evaluation: an implementation evaluation and an outcome evaluation. It will be important to determine how implementation can be improved during and after TAKERS, and it will be important to know if TAKERS is reaching its intended outcomes.

Evaluator

TAKERS would benefit from an internal evaluator with consultation from an external evaluator. An internal evaluator would know the key areas in which the effectiveness of the program should be evaluated. The internal evaluator would also have access to the key
stakeholders to get their feedback and suggestions for improvement. However, an external evaluator will be further removed from the program and may be able to have objective evaluation in areas that may not occur to me. In addition, the external evaluator would have more access to resources, broader expertise in evaluation and perhaps with online learning (W. K. Kellogg Foundation, 2004).

There are several key skills that could be helpful to the internal and external evaluators. First, cross cultural programs need cultural sensitivity and need to be skilled with incorporating different perspectives (W. K. Kellogg Foundation, 2004). TAKERS will likely eventually be translated into Spanish; and therefore, speaking Spanish would be helpful though not necessary. Some ability to incorporate Latino culture and demonstrate cultural competence in the evaluation and working relationship would be very useful. Also, the development of this program is a team effort, and the evaluation will be also. Therefore, team management skills would be very helpful in coordinating the evaluation efforts, particularly for the internal evaluator.

Stakeholders

The stakeholders that need to be involved in the evaluation are Dr. Maria Ferris, the participants, participants’ parents, and to some extent the Renal Research Institute (RRI). Since the patients involved in this study will likely also be cross-enrolled in the longitudinal study being conducted by Dr. Maria Ferris with measuring TRxANSITION outcomes, some goals and evaluation methods may need to be used for all patients so that they information can be used for both studies. Dr. Ferris is continuously involved in the progress of TAKERS for this reason.

The participants and participants’ parents need to be involved since they will be using the program. If they deem the program not useful, not interesting, or do not want to participate for some other reason, the researchers need to be aware of that information since the program is intended for their use. The participants will be involved by periodic questionnaires about the ease of use, enjoyment, and usefulness of the program. There will likely also be focus groups held to garner their input before the study begins.
Lastly, the RRI provided funding specifically for TAKERS to try to increase the self-management and efficacy skills of youth with chronic kidney disease. Therefore, the evaluators will need to evaluate TAKERS’ effectiveness in accomplishing this goal. Though RRI may not have a specific representative providing input on the evaluation, TAKERS must stay consistent with the grant proposal that was submitted to the RRI for funding.

**Challenges**

One of the challenges is the limitation to the TAKERS budget. This is one of the most common constraints of evaluating a project (Bamberger, Rugh, & Mabry, 2006). There is only a small amount of funding, and most of the researchers involved with TAKERS are not paid. However, there is a group of undergraduate and graduate students that are working on TAKERS in addition to a few paid employees. Therefore, the evaluation must be tailored to be accomplished by the current group of staff members and volunteers.

**Evaluation Study Design**

TAKERS study design is a “Two-group, Pre-Test/Post-Test, with Random Assignment,” also called a randomized trial (Issel, 2009). In this design, individuals from the target audience, patients aged 12-29 with chronic kidney disease, are randomized into two groups. One group receives the intervention, which is participation in the TAKERS module components. The other group does not participate in the intervention, which means these patients receive standard medical care. Each group will be evaluated using the same measurement tools at the beginning of the study and at the end of the study. This format will help determine the effectiveness of the program by comparing it to standard medical care. It will also help determine the amount of growth in knowledge and skills of all participants involved in TAKERS and those involved in standard care.

In addition, observational data will be collected via focus groups and interviews. The focus groups will be conducted at the beginning of the study with patients that may not actually participate in the full study as described in the previous paragraph. The interviews will be
conducted as participants come to UNC Kidney Center for their regularly scheduled appointments.

**Evaluation Methods**

Since TAKERS is a 3 year study, the patients will be evaluated at baseline, after completing TAKERS, and then periodically every 6 – 12 months. As mentioned previously, participants may also be interviewed periodically as they come to UNC Kidney Center for their regularly scheduled appointments. The patients will be evaluated on three main categories: readiness for transition, ability to read a food label, and self-efficacy.

To evaluate the patients’ readiness for transition, several validated scales will be used. First, the UNC TR\textsubscript{ANSITION} Scale\textsuperscript{TM} will be used to determine an overall transition readiness score, which will be administered by research assistants in the clinic. The other surveys can be administered online or at the clinic without research assistants’ presence. They include the STAR\textsubscript{X} Transition Readiness Survey, Morisky 8 General Medication Adherence Scale, Medical Passport Usage Survey and the TAKERS pre-test/post-test. Participants’ Health Literacy will be evaluated using the Newest Vital Sign and Prescription Label Test. Participants’ self-efficacy will be measured using the Health Behavior Survey. All of these evaluation items are included in the appendix for further review.

To evaluate participants’ overall experience with TAKERS, understandability of the material, technical difficulties with TAKERS, and other patient-centered evaluation questions, patients will complete an “End of TAKERS Survey” with multiple choice and open-ended questions. For more process-related questions, the research assistants will also review the TAKERS Activity Log for information such as the amount of time it took for most patients to complete the various program components. For implementation evaluation, the Research Assistants will review the organization record to determine if all participants took the appropriate baseline and follow-up evaluations and received their medical passport. Lastly, most long term
outcomes will be evaluated via medical record review, interviews and/or a Follow-up TAKERS survey.

**Evaluation Planning Tables**

**Short Term Objectives**

Short Term Objective 1

After completing TAKERS, all participants will improve their readiness for transition based on:

- UNC TRxANSITION Scale™: At least 80% of participants will earn a score of at least an 8/10.
- TAKERS pre/post-test: At least 80% of participants will earn at least an 80% on the post-test.
- STARx Transition Readiness Survey: At least 80% of participants will respond with at least 3 out of 5 on each section of the survey.
- Morisky 8 General Medication Adherence Scale: At least 80% of participants will have a score of 5 or less.
- Medical Passport: All participants will have a medical passport. The medical passport survey will demonstrate that they carry and use their medical passport when needed.

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have at least 80% of the patients earned at least an 8/10 on the UNC TRxANSITION Scale™?</td>
<td>Patients</td>
<td>UNC TRxANSITION Scale™</td>
</tr>
<tr>
<td>Have at least 80% of the patients earned an 80% on the post-test?</td>
<td>Patients</td>
<td>TAKERS pre/post-test</td>
</tr>
<tr>
<td>Have at least 80% of participants respond with at least 3 out of 5 or each section of the STARx Transition Readiness Survey?</td>
<td>Patients</td>
<td>STARx Transition Readiness Survey</td>
</tr>
<tr>
<td>Do at least 80% of participants have a score of 5 or less on the Morisky 8</td>
<td>Patients</td>
<td>Morisky 8 General Medication Adherence Scale</td>
</tr>
<tr>
<td>General Medication Adherence Scale?</td>
<td>Patients</td>
<td>Medical Passport Usage Survey</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>----------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Do patients carry and use their medical passport when appropriate?</td>
<td>Patients</td>
<td>TAKERS Activity Log</td>
</tr>
<tr>
<td>How long did it take to complete the TAKERS program components?</td>
<td>Patients</td>
<td>TAKERS Activity Log</td>
</tr>
<tr>
<td>Did the participants have any technical difficulties with running the program on their (computer, phone, tablet)?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Did the participants enjoy the TAKERS module?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>How understandable was the information presented in TAKERS?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>How can TAKERS be improved?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Did all participants receive a medical passport?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Were all the baseline measures administered?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
<tr>
<td>Did all participants complete all of the end of TAKERS evaluations after completing TAKERS?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
</tbody>
</table>

**Short Term Objective 2**

After completing TAKERS, all participants will improve their health literacy.

- **REALM (Rapid Estimate of Adolescent Literacy in Medicine):** This will only be used to assess baseline literacy level.
- **Newest Vital Sign:** At least 70% of participants will have a score of at least 4.
- **Prescription Label Test:** Goal to be determined (Assessment not yet created).

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have at least 70% of patients scored at least a 4 on the Newest Vital Sign?</td>
<td>Patients</td>
<td>Newest Vital Sign</td>
</tr>
<tr>
<td>Question</td>
<td>Participants</td>
<td>Evaluation Methods</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------</td>
<td>--------------------------------------------------------</td>
</tr>
<tr>
<td>Have patients improved their score on the Prescription Label Test?</td>
<td>Patients</td>
<td>Prescription Label Test</td>
</tr>
<tr>
<td>Did all participants take the REALM, Newest Vital Sign, and Prescription Label Test at baseline?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
<tr>
<td>How helpful was TAKERS in learning to read nutrition labels?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>How helpful was TAKERS in learning to read prescription labels?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>How understandable was the material about prescription labels and nutrition labels?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Did participants enjoy the section on prescription labels and nutrition labels?</td>
<td>Patients</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>What can be improved in this section?</td>
<td>Patients, Research Assistants, Parents, Other stakeholders</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Did all participants take the Newest Vital Sign and the Prescription Label Test after completion of TAKERS?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
</tbody>
</table>

**Short Term Objective 3**

After completing TAKERS, all participants will increase their level of self-efficacy.

- Health Behavior Survey: Goal to be determined (Validated assessment being requested).

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have patients increased their level of self-efficacy?</td>
<td>Patients</td>
<td>Health Behavior Survey</td>
</tr>
<tr>
<td>Have the parents seen any actions that have shown increased self-efficacy?</td>
<td>Parents</td>
<td>Parent version of the End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>Have the primary care providers noticed any actions that have shown an increase in self-efficacy?</td>
<td>Health Care Providers</td>
<td>PCP version of the End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
<tr>
<td>What parts of TAKERS could help further improve patient self-efficacy?</td>
<td>Patients, Parents, Health Care Provider</td>
<td>End of TAKERS survey with multiple choice and open-ended questions</td>
</tr>
</tbody>
</table>
**Long Term Objectives**

As long as patients remain in the TRXANSITION database, data may be collected on their health outcomes periodically to follow-up on the following long term objectives:

**Long Term Objective 1**

Participants will have discussed transitioning from pediatric care to adult care with their health care provider (Child and Adolescent Health Measurement Initiative, 2010; U.S. Department of Health and Human Services, 2012a)

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have participants discussed transitioning from pediatric care to adult care with their primary care provider?</td>
<td>Patients</td>
<td>Follow-up TAKERS Survey, one on one Interviews</td>
</tr>
<tr>
<td>What were the challenges to discussing transitioning with their primary care provider?</td>
<td>Patients</td>
<td>Follow-up TAKERS Survey, one on one Interviews</td>
</tr>
<tr>
<td>How did the patients bring up the topic of transitioning medical care with their primary care provider?</td>
<td>Patients</td>
<td>Follow-up TAKERS Survey, one on one Interviews</td>
</tr>
</tbody>
</table>

**Long Term Objective 2**

Patients will have more positive transition outcomes such as decreased morbidity and avoidable hospitalizations, increased quality of life and improved self-management skills.

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients have fewer avoidable hospitalizations than non-participants?</td>
<td>Research Assistants, Patients</td>
<td>Medical Record Review, Follow-up TAKERS Survey</td>
</tr>
<tr>
<td>Do patients have increased quality of life than non-participants?</td>
<td>Patients</td>
<td>Follow-up TAKERS Survey</td>
</tr>
<tr>
<td>Do patients have improved self-management skills as compared to non-participants?</td>
<td>Patients</td>
<td>Follow-up TAKERS Survey</td>
</tr>
</tbody>
</table>

**Long Term Objective 3**
Patients will maintain higher scores than baseline on the UNC TRxANSITION Scale™ and STARx Transition Readiness Survey among other measures used previously if time allows for the completion of other methods of evaluation.

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Participants</th>
<th>Evaluation Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients have higher scores than baseline on the transition assessment measures?</td>
<td>Participants</td>
<td>UNC TRxANSITION Scale™, TAKERS pre/post-test, STARx Transition Readiness Survey, Morisky 8 General Medication Adherence Scale, Newest Vital Sign, Prescription Label Test</td>
</tr>
<tr>
<td>Were these evaluations administered every 6 months to 1 year?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
<tr>
<td>What were the challenges in administering these measures at the stated intervals?</td>
<td>Research Assistants</td>
<td>Organizational Record</td>
</tr>
</tbody>
</table>

**IRB Considerations**

There are no key risks for human subjects with completing TAKERS and participating in the online curriculum. There are however, concerns about the confidentiality of the data. In order to address these concerns, the TAKERS research team has a series of structures in place to ensure that only those who need access to the data can access it.

**Confidentiality of Data**

Focus groups will be held in private rooms and will be voluntary in nature. If any participant opposes being recorded, the digital recorder will not be used during that session, the participant will be asked questions at a different time or different session, or the participant will be asked not to participate.

All participants are assigned a unique study ID. All data collected will be coded using their ID. Hard copy data will be stored in a filing room that is locked and only accessible by an ID card that has been granted access permission. Data analysis will be kept in a password protected
database. All subjects will be assigned unique study IDs that will be used in lieu of any personal identifiers.

Phone conversations will take place in private rooms and will not be recorded. All mail correspondence will be sent in plain, Department of Medicine envelopes with only the participant's mailing address.

The data from semi-annual chart review will be entered into a password-protected program and stripped of identifiers to ensure confidentiality. Names will be kept in a separate secure database. The security of the database will be maintained using password-restricted access to computers and files.

**Consenting Human Subjects**

Several Consent forms are used for TAKERS in order to ensure that all participants are consented for the appropriate part of the study. First, there is a general consent form which most participants can sign for general participation in all parts of the study. There are also consent forms children aged 7-14 and children aged 15-17. These forms must be accompanied by the parental permission form. Finally, there is a separate consent form for the focus groups.

**Type of IRB application**

The TAKERS game requires a full IRB form for several reasons. It involves human subjects who will be providing information about themselves. TAKERS will be accessing patient medical records, and the study will be conducted with children, their parents, and may also involve their primary care providers. The IRB was approved on May 28, 2013. The IRB number for this study is 13-0041. The title is “TAKERS: Take your meds, Ask questions, Know your condition, Eat Healthy, Read Labels, Seek support.”

**Dissemination Plans**

The findings of the study will be published in medical and scientific literature. The goal of this project is to provide more data on the effectiveness of computer-based learning for youth with chronic conditions. It is hoped that the results will show an improved ability to read a food
label, efficacy, and readiness for transition; however, either way, this data will inform future individuals involved in patient education about the usefulness of computer-based learning. It will also serve as a source of recommendations for others who may have interest in developing similar programs.

Therefore, as the results are analyzed, the TAKERS research team will begin to write papers to be submitted to several medical journals. Also, the results may also be described on the UNC TRxANSITION website and with other partners in the field of transitioning to health care. In addition, the results may be shared with professional medical organizations, especially those specific to Nephrologists.

**Discussion**

**Current Status of TAKERS**

To date, one main portion of TAKERS has been developed through partnerships with students and faculty of the UNC Computer Science Department and the UNC Kidney Center TRxANSITION team. The UNC Computer Science Department faculty (Dr. Diane Pozefsky) and students (Sai Vennam, Matthew Pittman, and Ameem Shaik) have developed the platform for the game, which is called “Space TAKERS.” At this point, this is the only portion of the program that will be implemented. Other components of the game that would provide videos of children in dialysis centers and more interactive educational modules may be implemented at another time. Also, despite the hard work of Dr. Pozefsky, we were unable to obtain permissions to implement Space TAKERS on smart phones or tablets. Therefore, it will be implemented only on laptops and desktop computers at this time.

Also, since we want to ensure that each participant enters their TRxANSITION ID number correctly before they play the game, Space TAKERS will be implemented solely in the UNC Kidney Center as patients come for their regularly scheduled appointments. The TRxANSITION ID number will allow the researchers to connect the users’ performance on
Space TAKERS with their sensitive medical information, which will be held on another more secure database.

The randomization process will be conducted differently than initially described. First, a pilot group of participants will answer the questions on paper and also by playing Space TAKERS. The question bank for Space TAKERS and for the paper will be the same. The children will be randomized to play the game first and take the paper test second; or they will take the paper test and then play the game second. This will help the researchers determine if the game platform is a comparable form of measurement of knowledge as paper and pencil.

The focus group component of this project has been put on hold for now. There are focus group questions that have been developed and submitted with the IRB for this project. Focus groups are still a goal of the project; however, there are no plans currently in place to implement this portion of the project.

Also, I am still working on writing several of the evaluation tools. The prescription label test will be incorporated into the TAKERS pre-test and Space TAKERS game instead of being a separate test. I am using resources provided by Dr. Stacy Cooper Bailey to develop these prescription label questions (Bailey, Sarkar, Chen, Schillinger, & Wolf, 2012; Wolf et al., 2011). I am also using materials from a validated test for dialysis patients in addition to information from the website kidneyschool.org to develop several of the knowledge-based questions (Cavanaugh et al., 2009). Dr. Ferris and I requested information to help develop the Health Behavior Survey (Aliasgharpour, Shomali, Moghaddam, & Faghihzadeh, 2012); however, we are still awaiting a response.

Also, several tools that would be used to follow-up with patients and primary care providers about TAKERS have not been developed yet such as the End of TAKERS survey with multiple choice questions and open-ended questions (for patients and for Primary Care Provider), the Follow-up TAKERS Survey (for long-term follow-up). In addition, the one-on-one interview questions for long-term follow-up have not been written.
Currently, the TAKERS Activity Log records information such as how many questions the participant has answered, how long they spent on it and at what level of game and question difficulty they were playing. If other data needs to be collected in the future, we would need to reach out to the computer science partners again to change some portions of the data retrieval. In addition, the organization record which would be used to keep track of items such as whether or not participants have completed evaluations has not yet been developed. However, the organizational record can be developed retrospectively as surveys are completed.

**Future Goals**

TAKERS will **continue** to have a bright future. In the next few weeks, my goals are to continue to develop a larger database of questions for Space TAKERS, find another individual to continue to work with this project, and possibly begin work on the Health Behavior Survey. Currently, the Space TAKERS game does not address some of the key targets of the UNC TRANSITION Scale™ such as health insurance, issues of employment, school and reproduction, adherence to doctor’s appointments, how to find a new doctor, and how to develop a support system. I hope to address several of these missing elements as I continue to build the question bank in the next few weeks. However, ideally, a strong educational curriculum should be developed to precede the Space TAKERS game. This would also help the patients learn much more material in an interactive way, and then use the Space TAKERS game as an engaging evaluation tool.

Those who continue this project will hopefully be able to develop some of the missing components needed to complete this project. Also, as the project continues, more individuals will be needed to implement the Space TAKERS game in the clinic and begin to collect and analyze data.

**Lessons Learned**

The process of planning this project has allowed me to learn about the many aspects involved in thoroughly planning and implementing a well-designed program. I have learned the
importance of grounding programs in current health standards such as Healthy People 2020 and current theories such as the Chronic Care Model and Health Belief Model in order to provide validated base of support for the components of the program.

Additionally, I have learned that programs are not static entities. As the planning process ensues, new ideas can change the direction of the program. Also, adding new partners creates new opportunities for creative ways of communication such as Drop Box or Google documents to keep all members informed. Other times, time constraints and lack of funding can require a redesign or re-prioritizing of program components. Program planning is a constantly changing process that requires flexibility and creativity to keep making progress towards the ultimate goal.

Finally, and most importantly, program planning and development takes time. The wide base of research, the great ideas of all team members, and busy schedules of all the partners are important components of building a program that take time. However, with TAKERS and other programs, the satisfaction of achieving a goal and changing lives is worth the time and effort it takes to create a well-developed program plan and evaluation.
Appendix
UNC TR\textsubscript{TRANSITION} Scale\textsuperscript{TM} for Adolescents and Young Adults:

**Instructions:** Read the question to the patient, and circle the choice on the right that best describes the patient’s response. Sum the scores for each section in the “Subtotal” row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the “Proportion”.

### Type of chronic health condition

<table>
<thead>
<tr>
<th>Question</th>
<th>Correct</th>
<th>Non-specific</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the name of your health condition?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>2. What physical symptoms do you experience because you have [name of health condition]?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>3. How might [name of health condition] affect your health in the future?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Sum the scores for this section Subtotal T* _____ out of 3

*Divide the subtotal by the number of applicable questions Proportion T*

### R\textsubscript{x}: Medications

<table>
<thead>
<tr>
<th>Question</th>
<th>Can name all</th>
<th>Can name some</th>
<th>Cannot name any</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>5. When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>6. What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>7. What could happen if you do not take [name each medication, vitamin, and supplement patient should be taking] like your doctor has asked you to?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
</tbody>
</table>

*Sum the scores for this section Subtotal R\textsubscript{x} _____ out of ____

*Divide the subtotal by the number of applicable questions Proportion R\textsubscript{x}*

---

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenion, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odom Institute.

Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09
### Adherence

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Sometimes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>8  In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or didn’t want to take it?</td>
<td>0.0</td>
<td>0.5</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>9  Do you usually have trouble remembering to take your medicines every day?</td>
<td>0.0</td>
<td>0.5</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>10 Do you usually come to your doctor appointments when they are scheduled?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
</tbody>
</table>

*Sum the scores for this section*  
Subtotal A ___ out of ___

*Divide the subtotal by the number of applicable questions*  
Proportion A

### Nutrition

<table>
<thead>
<tr>
<th>Question</th>
<th>Knows definitely</th>
<th>Has an idea</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>12 Are you supposed to follow any special diet because you have [name of health condition]?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>13 [if the patient is on a special diet] What are examples of the foods and/or drinks that you should have more or less of?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Sum the scores for this section*  
Subtotal N ___ out of ___

*Divide the subtotal by the number of applicable questions*  
Proportion N
### Self-management skills

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Sometimes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 Do you usually remember to take your medicines on your own?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>15 Does someone usually have to remind you to take your medicines?</td>
<td>0.0</td>
<td>0.5</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>16 Do you usually call in your prescription refills yourself?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>17 Do you usually pick-up refills from the pharmacy yourself?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>18 Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>19 Do you usually make your own doctor appointments?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>20 [if the patient has medical procedures to perform] Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
<td></td>
</tr>
</tbody>
</table>

**Sum the scores for this section**

| Subtotal S | __ out of __ |

**Divide the subtotal by the number of applicable questions**

| Proportion S |

**Note:** Some patients may be too young for the following questions to be appropriate. Score these patients as 0’s, as these are important skills not yet obtained.

### Issues of reproduction

<table>
<thead>
<tr>
<th>Question</th>
<th>Male</th>
<th>Female</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>21 Would your health condition likely affect your ability to:</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>[if female] become pregnant?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[if male] get someone pregnant?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22 [Females only] What are risks you might face if/when you become pregnant because you have [name of health condition]?</td>
<td>1.0</td>
<td>0.5</td>
<td>N/A</td>
</tr>
<tr>
<td>23 [Females only] Do you take any medicines that would be harmful to an unborn baby if you became pregnant?</td>
<td>1.0</td>
<td>0.5</td>
<td>N/A</td>
</tr>
<tr>
<td>24 Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD’s?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

**Sum the scores for this section**

<table>
<thead>
<tr>
<th>Subtotal I</th>
<th>Male</th>
<th>Female</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Divide the subtotal by the number of applicable questions**

<table>
<thead>
<tr>
<th>Proportion I</th>
<th>Man</th>
<th>Woman</th>
<th>N/A</th>
</tr>
</thead>
</table>
### Trade / School

<table>
<thead>
<tr>
<th>Question</th>
<th>Knows definitely</th>
<th>Has an idea</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>25  What are your future plans in regards to school and/or a job?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Sum the scores for this section*  
Subtotal T ____ out of 1

*Divide the subtotal by the number of applicable questions*  
Proportion T

### Insurance

<table>
<thead>
<tr>
<th>Question</th>
<th>Knows definitely</th>
<th>Has an idea</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>26  What is health insurance and why is it important to have?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>27  What is the name of your current health insurance provider?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>28  [If he/she is currently insured] At what age will your current health insurance coverage end?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>29  How can you get health insurance coverage for yourself when you are an adult?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Sum the scores for this section*  
Subtotal I ____ out of ____

*Divide the subtotal by the number of applicable questions*  
Proportion I

### Ongoing support

<table>
<thead>
<tr>
<th>Question</th>
<th>Self</th>
<th>Parents/friends</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>30  When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Sum the scores for this section*  
Subtotal 0 ____ out of 1

---

*Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O’Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.*

*Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09*
# New health care providers

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Knows definitely</th>
<th>Has an idea</th>
<th>Does not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>31</td>
<td>When it comes time for you to switch to an adult doctor, how will you find one?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>32</td>
<td>In order to get your medical records transferred to another doctor, what is required to make this happen?</td>
<td>1.0</td>
<td>0.5</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Sum the scores for this section

Subtotal N = ______ out of 2

Divide the subtotal by the number of applicable questions

Proportion N

## Raw total score

Sum all section subtotals here (max 32)

## T.R.A.N.S.I.T.I.O.N Score™

Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)

http://unckidneycenter.org/hcprofessionals/transition.html

---

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*Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09*
STARx Transition Readiness Questionnaire

DIRECTIONS

Patients with chronic health conditions need to have special skills and do special tasks to stay healthy.

On the following pages, please check the box underneath the answers that describe you most.

If you do not understand a question, just ask for help. We’re here to help you ☐
Section 1 :

- How often have you done the following things?
- Please check the box that tells how often you have done each thing in the **PAST 3 MONTHS**.

<table>
<thead>
<tr>
<th>In the past 3 months ...</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
<th>Not Needed for my care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often did you make an effort to understand what your doctor told you?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. How often did you take your medicines on your own?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. How often did you ask your doctor or nurse questions about your illness, medicines or medical care?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. How often did you make your own appointments?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. How often did you need someone to remind you to take your medicines?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. How often did you use the internet, books or other guides to find out more about your illness?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. How often did you forget to take your medicines?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. How often did you work with your doctor to take care of new health problems that came up?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Section 2:

- Some patients know a lot about their health and some patients don't.
- How much do you know?
- Please check the answer that best describes how much you feel you know TODAY.

<table>
<thead>
<tr>
<th></th>
<th>Nothing</th>
<th>Not Much</th>
<th>A little</th>
<th>Some</th>
<th>A Lot</th>
<th>Not Needed for my care</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. How much do you know about your illness?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. How much do you know about taking care of your illness?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. How much do you know about what will happen if you don't take your medicines?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### Section 3:

- Some patients may find it hard to do certain things.
- How easy or hard is it for you to do the following things?
- Please check the answer that best describes how you feel TODAY.

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Very Hard</th>
<th>Somewhat Hard</th>
<th>Neither Hard nor Easy</th>
<th>Somewhat Easy</th>
<th>Very Easy</th>
<th>Not Needed for my care</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. How easy or hard is it to talk to your doctor?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. How easy or hard is it to make a plan with your doctor to care for your health?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. How easy or hard is it to see your doctor by yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. How easy or hard is it to take your medicines like you are supposed to?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. How easy or hard is it to take care of yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. How easy or hard do you think it will be to move from pediatric to adult care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Morisky 8 General Medication Adherence Scale

You indicated that you are taking medication for your (identify health concern, such as “high blood pressure”). Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your [health concern] medication. Interviewers may self identify regarding difficulties they may experience concerning medication-taking behavior.

<table>
<thead>
<tr>
<th>(Please circle the correct number)</th>
<th>No=0</th>
<th>Yes=1</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you sometimes forget to take your [health concern] pills?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your [health concern] medicine?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. When you travel or leave home, do you sometimes forget to bring along your [health concern] medication?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Did you take your [health concern] medicine yesterday?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. When you feel like your [health concern] is under control, do you sometimes stop taking your medicine?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Taking medication everyday is a real inconvenience for some people. Do you ever feel hassled about sticking to your blood pressure treatment plan?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. How often do you have difficulty remembering to take all your medications? (Please circle the correct number)
   - Never/Rarely...........................................0
   - Once in a while.....................................1
   - Sometimes...........................................2
   - Usually............................................3
   - All the time.......................................4


For additional information, contact: Donald E. Morisky, Sc.D., M.S.P.H., Sc.M., e-mail: dmorisky@ucla.edu; phone: (310) 825-8508
Medical Passport Survey (completed by patient)

Q1 What is your transition ID number?

Q2 In the last 3 months, how many doctor appointments have you had?

Q3 At how many of these doctor appointments did you show someone your medical passport?

Q4 In the last 3 months, how many times have you gone to the emergency room?

Q5 Out of those times you have gone to the emergency room, how many times did you show someone your medical passport?

Q6 Where have you used your medical passport? (please mark all that apply)
   - showed it to a doctor and/or nurse when I had an appointment
   - showed it to a doctor and/or nurse when I was in the emergency room
   - showed it to a paramedic when I had an emergency and the ambulance was called
   - used it at home to learn about my medicines
   - used it in the community as an identification (ID) card
   - I have not used my medical passport during the last 3 months.

Q7 Have you ever used your medical passport to do any of the following: (please mark all that apply)
   - Learn the name of your health condition
   - Learn the name of your medicine(s)
   - Learn when you are supposed to take your medicine(s)
   - Learn why you take each of your medicine(s)
   - Get your medical provider's phone number
   - Learn the name of your health insurance
   - Other (please tell us what other information you used your medical passport to obtain)
   - I have not used my medical passport during the last 3 months.

Q8 Do you carry your medical passport with you?
   - Yes, I always have it with me
   - Sometimes I carry it with me
   - No, I never carry it with me

Q9 During an average week, how many days do you carry your medical passport with you?
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
Q10 If you DO NOT carry your medical passport with you everyday, please mark all of the reasons below that explain why.
- I don't have a wallet or purse to carry it in
- I don't like the medical passport
- I don't want other people to see it
- Someone else carries it for me
- I lost it
- I don't know why I don't carry it
- I carry it with me everyday

Q11 Has your medical passport been useful?
- Yes
- No

Answer If Has your medical passport been useful? Yes Is Selected

Q12 If YES, please tell us how it has been useful.

Answer If Has your medical passport been useful? No Is Selected

Q13 If NO, please tell us why it hasn't been useful.

Q14 Would you recommend this medical passport to young people like yourself who also have a medical condition?
- Yes
- No

Answer If Would you recommend this medical passport to young people... Yes Is Selected

Q15 If YES, please tell us why you would recommend it.

Answer If Would you recommend this medical passport to young people... No Is Selected

Q16 If NO, please tell us why you would not recommend it.
RAPID ESTIMATE OF ADOLESCENT LITERACY IN MEDICINE (REALM) Teen©

Terry Davis, PhD  Joe Bocchini, MD  Sandy Long, PhD  Michael Wolf, PhD

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>eye</td>
<td>fever</td>
<td>nutrition</td>
</tr>
<tr>
<td>pill</td>
<td>pimple</td>
<td>alcoholism</td>
</tr>
<tr>
<td>fat</td>
<td>virus</td>
<td>antibiotic</td>
</tr>
<tr>
<td>skin</td>
<td>calories</td>
<td>complications</td>
</tr>
<tr>
<td>throat</td>
<td>allergy</td>
<td>delinquency</td>
</tr>
<tr>
<td>blood</td>
<td>marijuana</td>
<td>penicillin</td>
</tr>
<tr>
<td>weight</td>
<td>pelvic</td>
<td>puberty</td>
</tr>
<tr>
<td>stress</td>
<td>asthma</td>
<td>menstrual</td>
</tr>
<tr>
<td>death</td>
<td>emergency</td>
<td>pneumonia</td>
</tr>
<tr>
<td>liquid</td>
<td>infection</td>
<td>constipation</td>
</tr>
<tr>
<td>disease</td>
<td>exercise</td>
<td>diagnosis</td>
</tr>
<tr>
<td>drug</td>
<td>medicine</td>
<td>nausea</td>
</tr>
<tr>
<td>mouth</td>
<td>violence</td>
<td>acne</td>
</tr>
<tr>
<td>ounce</td>
<td>prevention</td>
<td>anemia</td>
</tr>
<tr>
<td>heart</td>
<td>suicide</td>
<td>hepatitis</td>
</tr>
<tr>
<td>risks</td>
<td>depression</td>
<td>adolescent</td>
</tr>
<tr>
<td>diet</td>
<td>prescription</td>
<td>bulimia</td>
</tr>
<tr>
<td>teaspoon</td>
<td>abnormal</td>
<td>fatigue</td>
</tr>
<tr>
<td>period</td>
<td>injury</td>
<td>anorexia</td>
</tr>
<tr>
<td>cancer</td>
<td>ointment</td>
<td>tetanus</td>
</tr>
<tr>
<td>stomach</td>
<td>seizure</td>
<td>bronchial</td>
</tr>
<tr>
<td>headache</td>
<td>diabetes</td>
<td>obesity</td>
</tr>
</tbody>
</table>

(Davis et al., 2006)
The Newest Vital Sign

Assessment

**Nutrition Facts**

<table>
<thead>
<tr>
<th>Serving Size</th>
<th>½ cup</th>
</tr>
</thead>
<tbody>
<tr>
<td>Servings per container</td>
<td>4</td>
</tr>
</tbody>
</table>

**Amount per serving**

<table>
<thead>
<tr>
<th>Calories</th>
<th>250</th>
<th>Fat Cal</th>
<th>120</th>
</tr>
</thead>
<tbody>
<tr>
<td>%DV</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total Fat</th>
<th>13g</th>
<th>20%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sat Fat</td>
<td>9g</td>
<td>40%</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>28mg</td>
<td>12%</td>
</tr>
<tr>
<td>Sodium</td>
<td>55mg</td>
<td>2%</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>30g</td>
<td>12%</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>2g</td>
<td></td>
</tr>
<tr>
<td>Sugars</td>
<td>23g</td>
<td></td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
<td>8%</td>
</tr>
</tbody>
</table>

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

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The content for this material was excerpted from *The Newest Vital Sign—A Health Literacy Assessment Tool* website available at: [http://www.newestvitalsign.org/nvs-resources.aspx](http://www.newestvitalsign.org/nvs-resources.aspx)

The views expressed in these documents, Web sites, or other products do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.
Score Sheet for the Newest Vital Sign Questions and Answers

**READ TO SUBJECT:** This information is on the back of a container of a pint of ice cream.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If you eat the entire container, how many calories will you eat?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> 1,000 is the only correct answer</td>
<td></td>
</tr>
<tr>
<td>2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container Note: If patient answers “two servings,” ask “How much ice cream would that be if you were to measure it into a bowl.”</td>
<td></td>
</tr>
<tr>
<td>3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> 33 is the only correct answer</td>
<td></td>
</tr>
<tr>
<td>4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> 10% is the only correct answer</td>
<td></td>
</tr>
</tbody>
</table>

**READ TO SUBJECT:** Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Is it safe for you to eat this ice cream?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> No</td>
<td></td>
</tr>
<tr>
<td>6. (Ask only if the patient responds “no” to question 5): Why not?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer:</strong> Because it has peanut oil.</td>
<td></td>
</tr>
</tbody>
</table>

**Interpretation**

Score of 0-1 suggests high likelihood (50% or more) of limited literacy
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.
References


