



Sample Transition Readiness Assessment for Youth

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date:

Name:

Date of Birth:

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

How confident do you feel about your ability to prepare for/change to an adult doctor?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

My Health

Please check the box that applies to you right now.

Yes, I know this

I need to learn

Someone needs to do this... Who?

I know my medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain my medical needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my symptoms including ones that I quickly need to see a doctor for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my own medicines, what they are for, and when I need to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines and medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how health care privacy changes at age 18 when legally an adult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, I think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to go to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a file at home for my medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a copy of my current plan of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get referrals to other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where my pharmacy is and how to refill my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get blood work or x-rays if my doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan so I can keep my health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family and I have discussed my ability to make my own health care decisions at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Sample Transition Readiness Assessment for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date:

Name:

Date of Birth:

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it for your child to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

How confident do you feel about your child's ability to prepare for/change to an adult doctor?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

My Health

Please check the box that applies to your child right now.

Yes, he/she knows this

He/she needs to learn

Someone needs to do this... Who?

My child knows his/her medical needs.

My child can explain his/her medical needs to others.

My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.

My child knows what to do in case he/she has a medical emergency.

My child knows his/her own medicines, what they are for, and when he/she needs to take them.

My child knows his/her allergies to medicines and medicines he/she should not take.

My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).

My child knows he/she can see a doctor alone as I wait in the waiting room.

My child understands how health care privacy changes at age 18.

My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.

Using Health Care

My child knows or can find his/her doctor's phone number.

My child makes his/her own doctor appointments.

Before a visit, my child thinks about questions to ask.

My child has a way to get to his/her doctor's office.

My child knows to show up 15 minutes before the visit to check in.

My child knows where to go to get medical care when the doctor's office is closed.

My child has a file at home for his/her medical information.

My child has a copy of his/her current plan of care.

My child knows how to fill out medical forms.

My child knows how to get referrals to other providers.

My child knows where his/her pharmacy is and how to refill his/her medicines.

My child knows where to get blood work or x-rays if his/her doctor orders them.

My child has a plan to keep his/her health insurance after ages 18 or older.

My child and I have discussed his/her ability to make his/her own health care decisions at age 18.

My child and I have discussed a plan for supported decision-making, if needed.



Sample Transition Readiness Assessment for Youth/Young Adults

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health, using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:

Name:

Date of Birth:

Transition and Self-Care Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

How confident do you feel about your ability to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

My Health

Please check the box that applies to you right now.

*Yes, I know
this*

*I need to
learn*

*Someone needs to
do this... Who?*

I know my medical needs.

I can explain my medical needs to others.

I know my symptoms including ones that I quickly need to see a doctor for.

I know what to do in case I have a medical emergency.

I know my own medicines, what they are for, and when I need to take them.

I know my allergies to medicines and the medicines I should not take.

I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.

Using Health Care

I know or I can find my doctor's phone number.

I make my own doctor appointments.

Before a visit, I think about questions to ask.

I have a way to get to my doctor's office.

I know to show up 15 minutes before the visit to check in.

I know where to go to get medical care when the doctor's office is closed.

I have a file at home for my medical information.

I know how to fill out medical forms.

I know how to get referrals to other providers.

I know where my pharmacy is and how to refill my medicines.

I know where to get blood work or x-rays done if my doctor orders them.

I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).

I understand how health care privacy changes at age 18 when legally an adult.

I have a plan so I can keep my health insurance after 18 or older.

My family and I have discussed my ability to make my own health care decisions at age 18.



Sample Transition Readiness Assessment for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date:

Name:

Date of Birth:

Transition and Self-Care Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it for your child to manage his or her own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

How confident do you feel about your child's ability to manage his or her own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

My Health

Please check the box that applies to you right now.

Yes, he/she knows this

He/she needs to learn

Someone needs to do this... Who?

My child knows his/her medical needs.

My child can explain his/her medical needs to others.

My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.

My child knows what to do in case he/she has a medical emergency.

My child knows his/her own medicines, what they are for, and when he/she needs to take them.

My child knows his/her allergies to medicines and medicines he/she should not take.

My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.

Using Health Care

My child knows or can find his/her doctor's phone number.

My child makes his/her own doctor appointments.

Before a visit, my child thinks about questions to ask.

My child has a way to get to his/her doctor's office.

My child knows to show up 15 minutes before the visit to check in.

My child knows where to go to get medical care when the doctor's office is closed.

My child has a file at home for his/her medical information.

My child has a copy of his/her current plan of care.

My child knows how to fill out medical forms.

My child knows how to get referrals to other providers.

My child knows where his/her pharmacy is and how to refill his/her medicines.

My child knows where to get blood work or x-rays if his/her doctor orders them.

My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).

My child knows he/she can see a doctor alone as I wait in the waiting room.

My child understands how health care privacy changes at age 18.

My child has a plan to keep his/her health insurance after ages 18 or older.

My child and I have discussed his/her ability to make his/her own health care decisions at age 18.

My child and I have discussed a plan for supported decision-making, if needed.

**Measuring the Preparation for Transition from Pediatric-Focused to Adult-Focused Health Care:
The Adolescent Assessment of Preparation for Transition (ADAPT) Survey**

Center of Excellence for Pediatric Quality Measurement

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July 2014

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Funding: Support for this work was provided by the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality and Centers for Medicare & Medicaid Services, CHIPRA Pediatric Quality Measures Program Centers of Excellence under grant number U18 HS 020513. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

How to cite this report:

CEPQM. *Measuring the Preparation for Transition from Pediatric-Focused to Adult Focused Health Care: The Adolescent Assessment of Preparation for Transition (ADAPT) Survey*. Boston, MA: Center of Excellence for Pediatric Quality Measurement; July 2014.

The Adolescent Assessment of Preparation for Transition (ADAPT) Survey

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Introduction

This document describes how to administer, analyze, and calculate scores from the Adolescent Assessment of Preparation for Transition (ADAPT) survey in a sample derived from either (a) a primary care or specialty practice in a hospital or community setting (hereafter referred to as a clinical program) or (b) a defined population of covered individuals (e.g., health plan, accountable care organization). A version of the survey was developed for each of these types of samples. These versions differ only in how the patient's physician or other health care provider is identified. The clinical program version should be used if a particular clinician of interest is known (generally the patient's "main provider" for his or her chronic illness). The health plan version can be used to identify the likely "main provider" if claims or billing data are available.

Instructions and recommendations are provided in the following sections:

- Overview of development of the ADAPT survey
- Generation of a sample frame
- Data collection protocols
- Response rate calculation and data cleaning
- Calculation of measure composite scores

Overview of development of the ADAPT survey

The ADAPT survey was developed at The Center of Excellence for Pediatric Quality Measurement (CEPQM) at Boston Children's Hospital. It is a validated, youth-reported measure of the quality of health care transition (HCT) preparation designed to be completed by 16- and 17-year-old patients receiving care from a pediatric-focused provider. It was designed and validated for use among youth with chronic health conditions. Its purpose is to measure the quality of transition preparation based on youth reports of whether specific, recommended aspects of care were received. Three composite scores summarize responses in key domains of HCT preparation:

1. Counseling on Transition Self-Management
2. Counseling on Prescription Medication
3. Transfer Planning

Development of the ADAPT survey included an extensive review of the HCT literature and existing quality measures; expert interviews; parent, adolescent, and young adult focus groups in three large US cities; cognitive interviews in three cities; national field test with 3 sites (one with youth cared for in specialty clinics at a freestanding pediatric hospital and two with health plans serving Medicaid enrollees); and psychometric analysis and composite development.

The complete ADAPT surveys are available in **Appendix A (Health Plan and Clinical Program versions, English)** and **Appendix B (Health Plan and Clinical Program versions, Spanish)**.

Generation of a sample frame

Eligibility

The ADAPT survey is intended to be completed by youth either (a) receiving health care services in a clinical program or (b) enrolled in a health plan or similar defined population. Eligibility for participation is based on the following criteria:

- Age 16 to 17 years old at the time of survey completion
- At least one chronic health condition
- At least one outpatient visit with a health care provider in the preceding 12 months
- For health plan sampling, current enrollment at the time of the survey and enrollment over the preceding 12 months (allowing for ≤ 45 day gaps during that period)

Identification of youth with chronic health conditions

The approach to selection of the sample varies depending on goals of quality measurement, the size of the patient population and the data available for identification. For a clinical program, patient registries, electronic health records, or patient panels can be used to determine eligibility for the survey. For example, a group practice might choose to survey patients receiving longitudinal care from a specific group of subspecialty providers.

For a health plan or other entity with access to administrative claims data, identification of patients for the ADAPT survey can be accomplished by applying the Pediatric Medical Complexity Algorithm (PMCA) to claims data. Use of this standard approach will identify a valid sample that can be compared across health plans or other entities. The PMCA is a recently developed, publicly available algorithm that identifies children with complex chronic disease in claims or hospital discharge data with good sensitivity and specificity.[1] The PMCA was developed as part of the Pediatric Quality Measures Program to classify levels of medical complexity for children with special health care needs. The PMCA assigns body system flags, based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes, to enable counts of affected body systems and subsequent assignment of patients to one of the two chronic disease categories: 1) noncomplex chronic disease (NC-CD), defined as a non-progressive and non-malignant chronic condition in **only one** body system; and 2) complex chronic disease (C-CD), defined as a chronic condition that is progressive or malignant or in which **more than one** body system is involved. As detailed below, a stratified random sample of patients identified by the PMCA was used in the validation studies of the ADAPT survey.

Exclusions

Patients who meet the eligibility criteria outlined above should generally be included in the ADAPT survey sample. However, the following categories of otherwise eligible patients should be excluded from the sample frame:

- Patients who request that they not be contacted
- Court/law enforcement involved patients (i.e., prisoners); this category does not include those residing in halfway houses
- Patients with a foreign home address (the U.S. territories – American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and Virgin Islands – are not considered foreign addresses and therefore are not excluded)
- Patients who cannot be surveyed because of local, state, or federal regulations

Note: Include patients in the sample frame unless there is positive evidence that they are ineligible or fall within an excluded category. If information is missing on any variable that affects survey eligibility when the sample frame is constructed, do not exclude the patient from the sample frame because of that variable.

Sample creation

Clinical programs or health plans utilizing the ADAPT survey should generate complete, accurate, and valid sample frame data files that contain all administrative information for each patient who meets the eligibility criteria. The minimum data elements for sample frame creation for the ADAPT survey are in Table 1 below.

Table 1: Sample frame elements for administration of the ADAPT Survey

Name of clinical program / health plan
State of participating clinical program / health plan
Patient or Member ID
Name of patient
Gender of patient
Date of birth
Home address
PMCA chronic condition category: Non-complex chronic, Complex chronic*
PMCA-identified body system(s)*
Names of the health care providers who have most frequently been the billing or treating provider for an encounter with the patient in the past 12 months (up to 3 names are selected for inclusion in the survey)
Length (in months) of continuous enrollment (ignoring gaps ≤45 days)*

*If using the PMCA to identify respondents

The data elements that are most critical to the success of data collection are accurate and complete patient/member names, clinical program or health plan names, and home address.

De-duplication

Duplication of patients within the survey sample may occur if, for example, information for an eligible patient is received from multiple clinical programs within one hospital or practice setting. Perform de-duplication using the medical record number or health plan member identification number.

Sample size

The sample size goal for the survey should account for:

- The accuracy of patient/member home address
- The anticipated response rate based on prior surveys of the same or similar populations

The ADAPT survey can be used to assess the quality of transition preparation in a health plan or state Medicaid program, or as a tool for ongoing quality improvement in clinical programs. We have based our sample size recommendations on prior evaluations of widely used national patient experience surveys that have determined sample size requirements for adequate reliability.[2, 3, 4] For health plan or state Medicaid program comparisons, we recommend at least 300 completed surveys per health plan. By extension, we also recommend this sample size for comparisons of performance among large delivery systems (e.g., large multispecialty practices or hospitals with a number of outpatient programs for youth with chronic illness). This estimate may be further refined in the future, as data are collected from a larger number of settings than was possible in the current field test. The example in Table 2 below shows the sample size calculation for a goal of 300 surveys for a health plan with a predicted response rate of 20 percent.

Table 2: Calculation of estimated sample size needed for a health plan

Goal	300 completed surveys
Predicted response rate	20 percent (= .2)
Minimum total sample size	$(300/.2)=1500$ per health system

The ADAPT survey may also be used to assess performance for individual clinical programs. The number of responses for each administration will vary with the size of the available patient pool and the intended use. While further study is needed to determine the recommended sample size required for comparisons across programs, an individual program may use this measure over time to guide and assess improvement efforts. In general, the survey is not designed to measure or compare the performance of individual health care providers.

Sampling procedure

For large practices, hospitals, or health plans, use Simple Random Sampling (SRS) to draw the desired final sample. To use SRS as the sampling method, randomly select the desired final sample size from all eligible patients. The chance that each patient will be selected should be equal for all patients. For smaller populations of interest (e.g., a single clinical program), it may be necessary to select all of the treated patients to receive the survey in order to achieve the desired sample size.

In the case of a health plan or other defined population for whom claims data are available, use the PMCA algorithm to identify eligible patients, then draw equally sized random samples from the identified non-complex chronic disease (NC-CD) group and complex chronic disease (C-CD) group.

Since the survey is mailed to parent(s)/guardian(s) of identified patients, sampling populations of adolescents whose sole chronic condition is a mental health condition may pose an unacceptable risk of a breach of confidentiality. In the validation studies of the ADAPT survey, youth in the NC-CD group with only a mental health condition were excluded due to privacy concerns. Youth in the C-CD group were included if they had a mental health condition concurrent with a health condition affecting another body system. In addition, the sampling procedure should ensure that no more than 20% of the patients in the NC-CD sample have a condition affecting any one body system.

Preparing sample files for survey administration

Once the sample has been selected, assign a unique survey identification number to each prospective respondent (sampled patient). This unique ID number should **not** be based on an existing identifier, such as a Social Security Number or a patient ID number. This number will be used **only** to track the respondents during data collection.

The sampling fraction of the total eligible population will vary depending on the overall size of the population. Some small clinical programs or health plans may not be able to obtain the minimum desired number of completed surveys. In such cases, survey **all** eligible patients or members in an attempt to obtain as many completed surveys as possible.

Data collection protocols

Mail protocol

This section lists recommended steps for administering the survey by mail.

- **Survey preparation**
 - **Question 1.** The survey must be personalized for each individual so that they respond in reference to a particular provider. For Question 1 of the survey (on page 1), we recommend using a sticker to list provider names.
- **Set up a toll-free number (or use an existing information line) to include in all correspondence with prospective respondents.** Train staff members to respond to questions. Maintain a log of these calls and review them periodically for common issues that arise.
- **Mail the survey addressed to the parent/guardian of the prospective respondents with a cover letter and a postage-paid envelope.** The cover letter should include instructions for the adolescent patient to complete and return the survey. For examples, see *English mailed survey materials (Appendix C)* and *Spanish mailed survey materials (Appendix D)*.
 - **Tips for the cover letter:**
 - Personalize the letter with the name and address of the intended recipient (parent/guardian).
 - Tailor the letter to include language that explains the purpose of the survey, the voluntary nature of participation, and the confidentiality of responses.
 - Include language in the letter that asks the parent or guardian to give the survey to their adolescent child.
 - Indicate that if the adolescent child is unable to complete the survey independently (e.g., due to developmental delay), then the survey should not be completed. Include a check box in the cover letter for the parent/guardian to indicate that the identified child is unable to complete the survey, and instruct the parent or guardian to return the blank survey and cover letter for tracking.
 - Note that non-participation will not affect the health care of either the parent/guardian or the adolescent child.
 - Have the letter signed by a representative of the clinical program or health plan.
 - Confirm that the reading level of the cover letter is appropriate for the population and meets all applicable regulatory requirements.
 - **Tips for the outside envelope:**
 - Make the envelope look “official” but not bureaucratic or like “junk mail.”
 - Place a recognizable sponsor’s name above the return address.
 - Mark the envelopes “change of service requested” in order to receive information to update records for respondents who have moved and to increase the likelihood that the survey will reach the intended respondent.
- **Maintain a database of returned surveys by unique survey identifier.** Each prospective respondent in the response tracking system should be assigned a survey result code that indicates whether he or she completed and returned the survey, was ineligible to participate in the study, could not be located, or refused to participate.
- **Send a second survey three weeks after the initial mailing.** To avoid mailing another survey to those who have already responded, finish entry of returned surveys into the database before mailing second surveys. Include in the second mailing a slightly adapted reminder letter to those parents whose

adolescent children have not responded to the first mailing and another postage-paid return envelope. Examples of the reminder letter can be found in the ***mailed survey materials, English (Appendix C)*** and ***mailed survey materials, Spanish (Appendix D)***.

- **Close data collection 10 weeks from the first survey mailing.**

Calculation of the response rate

The response rate is the total number of completed surveys divided by the total number of surveys mailed, excluding from the denominator those that are either undeliverable or are returned with the indication that the patient does not meet eligibility criteria or is unable to complete the survey independently.

Numerator

- ***Completed surveys:*** A survey should be considered *complete* if it has responses for greater than 50% of questions 4-8, or if a respondent answers “None” to question 3.

Denominator

- ***Completed surveys plus non-responses:*** Non-responses include all surveys mailed but not returned, except for the following exclusions:
 - ***Undeliverable:*** The survey was returned by U.S. Mail as undeliverable. “Undeliverable” should not be assumed merely because of non-response.
 - ***Patient ineligible:*** The survey was returned with clear indication that the patient does not meet eligibility criteria (e.g., ineligible age or lack of a chronic health condition).
 - ***Patient unable to complete survey independently:*** This must be indicated by the appropriate checkbox in the cover letter or equivalent clear indication by the parent/guardian that the patient is unable to complete the survey independently (e.g., due to cognitive limitation).

Data cleaning protocols

Basic data cleaning procedures that include identifying out-of-range values, replacing numeric missing values with codes for “missing,” and checking for high missing rates for individual items are recommended prior to analysis of survey responses. In addition, “forward cleaning” of items that could be legitimately skipped also is recommended: if an item was supposed to be skipped because of the response to a screening question but was not, then replace the dependent response with the value “missing”. The value of a screening response should not be changed because a response was present for an item that should have been legitimately skipped. For a more detailed description of the data cleaning approach, see ***Decision rules and coding guidelines (Appendix E)***.

Calculation of measure composite scores

There are three domain-level composites included in the ADAPT survey. The calculation of composite scores is described below.

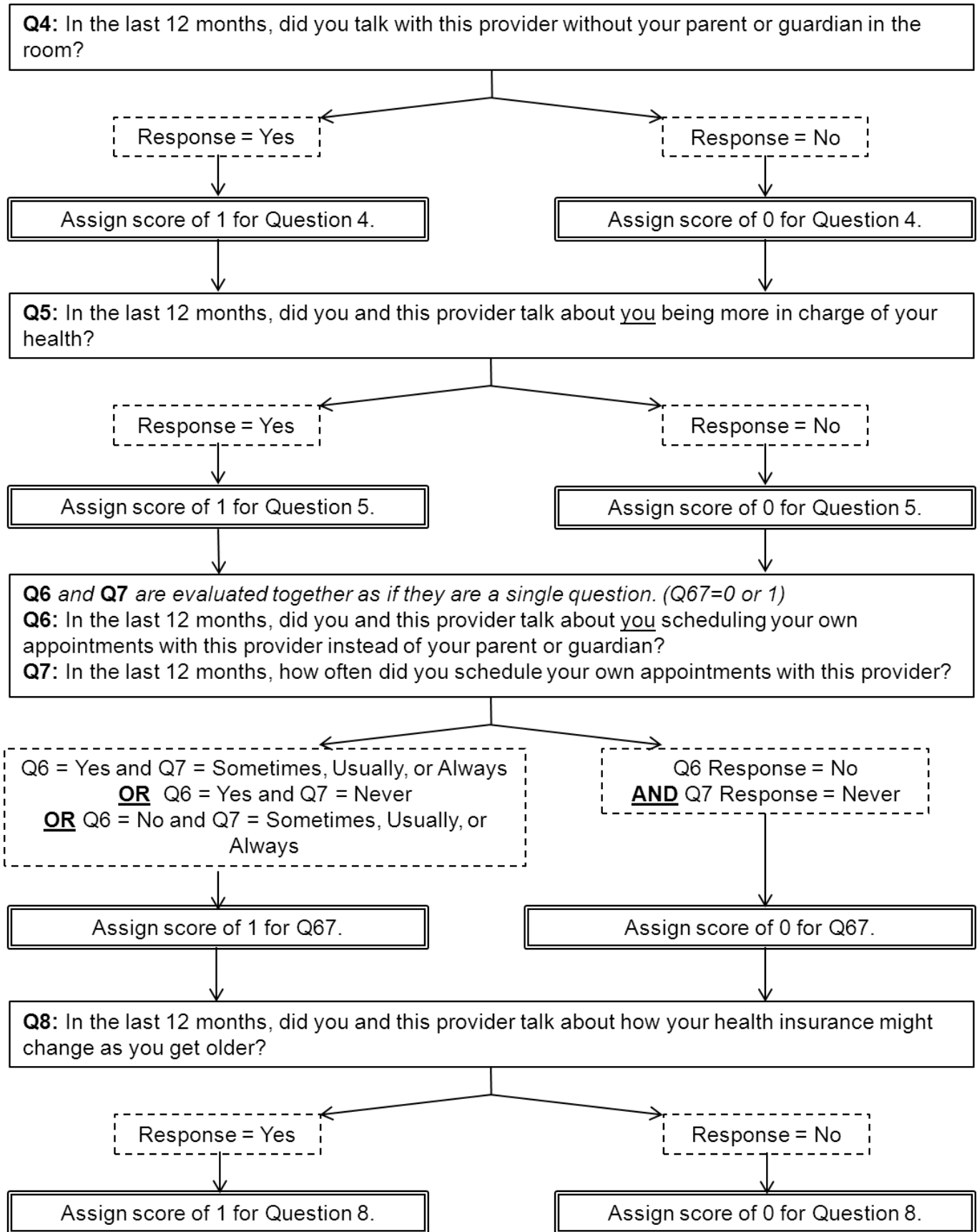
Counseling on transition self-management:

This composite is produced by combining responses to five questions:

- Q4: In the last 12 months, did you talk with this provider without your parent or guardian in the room?
- Q5: In the last 12 months, did you and this provider talk about your being more in charge of your health?
- Q6: In the last 12 months, did you and this provider talk about your scheduling your own appointments with this provider instead of your parent or guardian?
- Q7: In the last 12 months, how often did you schedule your own appointments with this provider?
- Q8: In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?

The five questions are scored as indicated in the following flow diagram:

Flow Diagram for Composite 1



Response options for questions 4-6 and 8 are “Yes” or “No”:

- Assign a score of 0 for No
- Assign a score of 1 for Yes

Response options for question 7 are “Never,” “Sometimes,” “Usually,” or “Always”:

- Assign a score of 0 for Never
- Assign a score of 1 for Sometimes, Usually, or Always

To calculate the measure composite score, Questions 6 and 7 are evaluated together as if they were a single question (Q67), the score of which is calculated as follows:

- Assign a score of 0 if Q6 = 0 AND Q7 = 0
- Assign a score of 1 if Q6 = 1 AND/OR Q7 = 1

The basic steps to calculate the composite score for a population are as follows:

- For each question, identify responses with non-missing values for that question
- For each question, calculate the proportion of responses with a score of 1
 - Numerator = the number of respondents with an individual question score of 1
 - Denominator = the number of respondents who completed the question (non-missing values)

- The proportion (P) for each question (Q) can be defined as follows:

Let $XQ_i = 1$ when question score = 1
 $= 0$ otherwise
 $YQ_i = 1$ when question has a score (0 or 1)
 $= 0$ otherwise

$$PQ = \frac{\sum_i XQ_i}{\sum_i YQ_i}$$

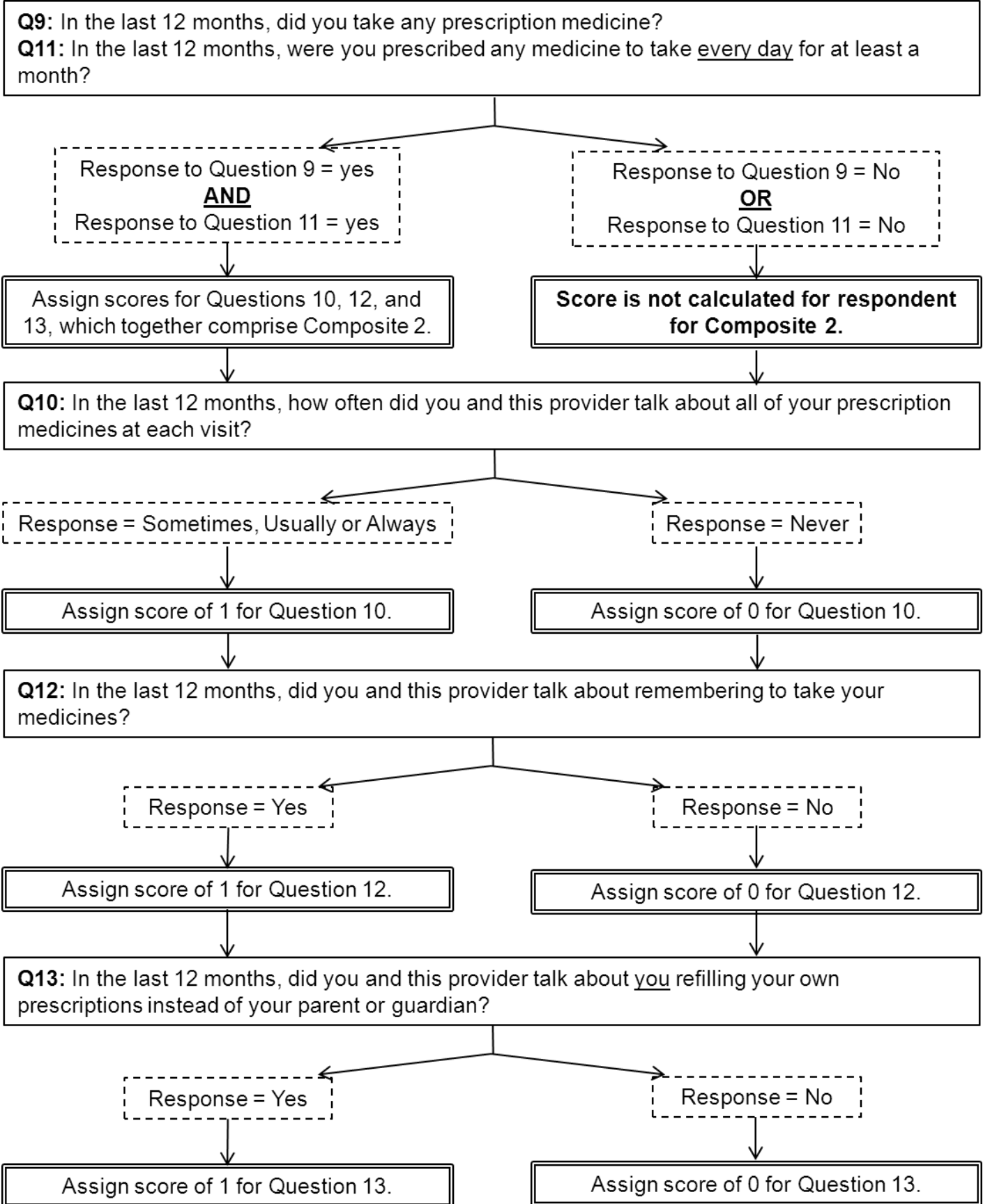
- Calculate the overall composite proportion (CP) for the domain:
 - Calculate P4, P5, and P8
 - Calculate P67
 - Calculate $(P4+P5+P67+P8)/4 = CP1$
- Calculate the Composite Score (CS) for the domain:
 - $CP1 \times 100 = CS1$

Counseling on prescription medication:

This composite score is calculated only for respondents who indicate on questions 9 (“in the last 12 months, did you take any prescription medicine?”) and 11 (“in the last 12 months, were you prescribed any medicine to take every day for at least a month?”) that they take prescription medication every day.

This composite is produced by combining responses to three questions, which are scored as indicated in the following flow diagram:

Flow Diagram for Composite 2



For each question, identify cases with non-missing values and for which the response for both question 9 and question 11 is “Yes”:

- Respondents who do not report taking prescription medicine every day (responses of “No” to either questions 9 or 11) are not included in the population for which this composite is calculated

The composite is produced by combining responses to questions 10, 12, and 13:

- Q10: In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?
- Q12: In the last 12 months, did you and this provider talk about remembering to take your medicines?
- Q13: In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?

Response options for question 10 are “Never,” “Sometimes,” “Usually,” or “Always”

- Assign a score of 0 for Never
- Assign a score of 1 for Sometimes, Usually, or Always

Response options for questions 12 and 13 are “Yes” or “No”

- Assign a score of 0 for No
- Assign a score of 1 for Yes

The basic steps to calculate the composite score for a population are as follows:

- For each question, identify responses with non-missing values for that question
- For each question, calculate the proportion of responses with a score of 1
 - Numerator = the number of respondents with an individual question score of 1
 - Denominator = the number of respondents who completed the question (non-missing values)
- The proportion (P) for each question (Q) can be defined as follows:

Let $XQ_i = 1$ when question score = 1
 $= 0$ otherwise
 $YQ_i = 1$ when question has a score (0 or 1)
 $= 0$ otherwise

$$PQ = \frac{\sum_i XQ_i}{\sum_i YQ_i}$$

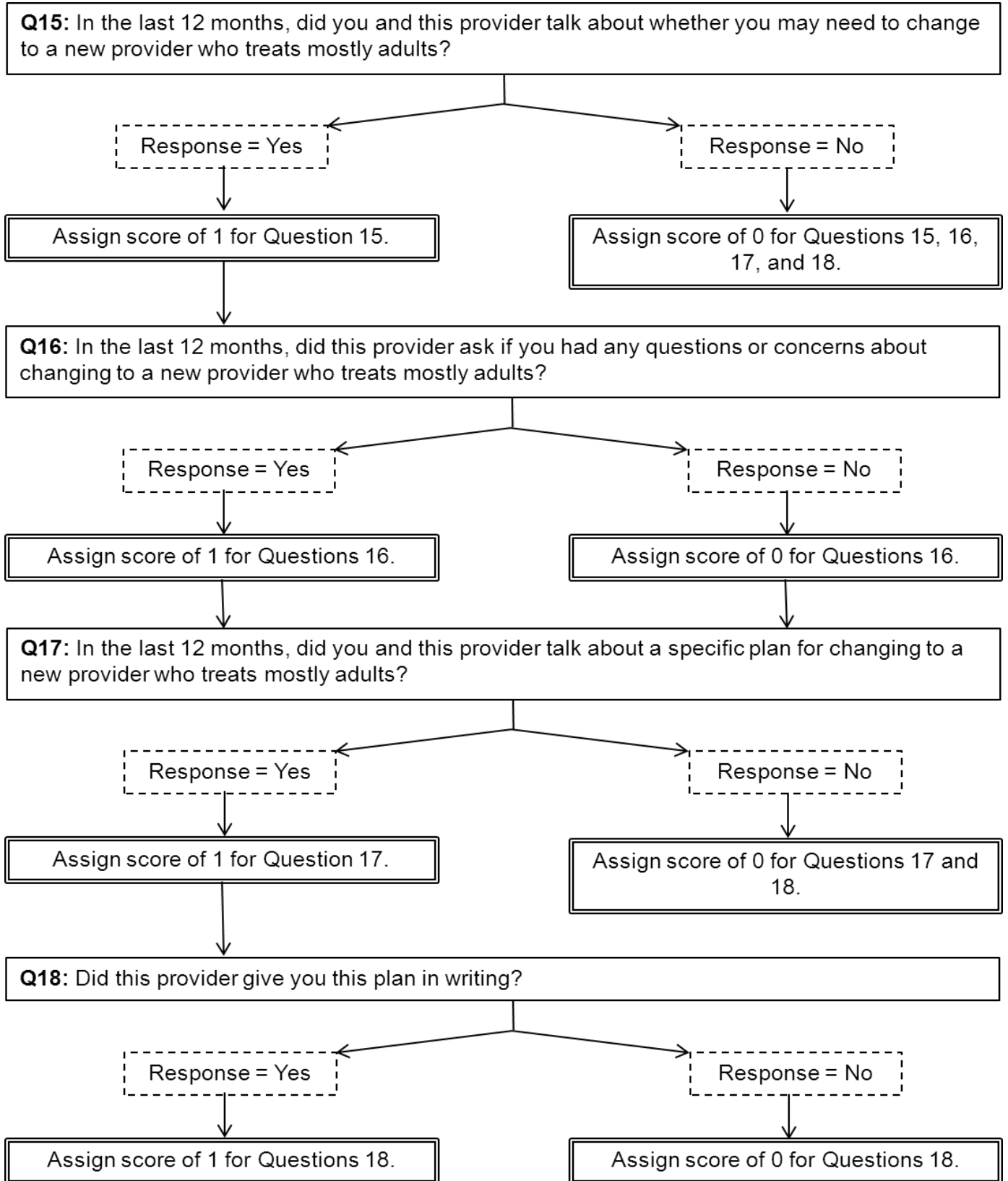
- Calculate the overall composite proportion (CP) for the domain:
 - Calculate P10, P12, and P13
 - Calculate $(P10+P12+P13)/3 = CP2$
- Calculate the Composite Score (CS) for the domain:
 - $CP2 \times 100 = CS2$

Transfer planning:

Only respondents who answer “Yes” or “Don’t Know” to question 14 (“Does this provider treat mostly children and teens?”) are included in the population for which this composite is calculated.

This composite is produced by combining responses to four questions, which are scored as indicated in the following flow diagram:

Flow Diagram for Composite 3



If a respondent answers “No” to question 15, the survey instructs them to skip questions 16, 17, and 18. Since the transfer planning assessed in these 3 questions is contingent on a “Yes” response to question 15, any respondent who answers “No” to question 15 is assigned a “No” response (score of 0) to questions 16-18.

If a respondent answers “No” to question 17, the survey instructs them to skip question 18. Since the response to question 18 is contingent on a “Yes” response to question 17, any respondent who answers “No” to question 17 is assigned a “No” response (score of 0) to question 18.

The basic steps to calculate the composite score for a population are as follows:

- Identify responses with non-missing values for question 15
- Assign scores for questions 15-18 as indicated above
- For each question, calculate the proportion of responses with a score of 1
 - Numerator = the number of respondents with an individual question score of 1
 - Denominator = the number of respondents who completed the question or were assigned a score of 0 as per above
- The proportion (P) for each question (Q) can be defined as follows:

Let XQ_i = 1 when question score = 1
 = 0 otherwise
 YQ_i = 1 when question has a score (0 or 1)
 = 0 otherwise

$$PQ = \frac{\sum_i XQ_i}{\sum_i YQ_i}$$

- Calculate the overall composite proportion (CP) for the domain:
 - Calculate P15, P16, P17, and P18
 - Calculate $(P15+P16+P17+P18)/4 = CP3$
- Calculate the Composite Score (CS) for the domain:
 - $CP3 \times 100 = CS3$

Acknowledgments

We would like to thank the following people who participated in the development of the ADAPT Survey:

Additional team members from Boston Children's Hospital and the Center for Survey Research, University of Massachusetts, Boston:

Carol A. Cosenza, MSW
Shannon C. Hardy, BA
Isabel Janmey, BA
Chelsea K. Johnson, BA
Jessica L. LeBlanc, BA
Lindsey L. Mahoney, BS
Mari M. Nakamura, MD, MPH
Shanna Shulman, PhD

Partners from AmeriHealth Caritas Pennsylvania and Texas Children's Health Plan

Members of Boston Children's Hospital Transition Measure Advisory Committee

Staff of the Center of Excellence for Pediatric Quality Measurement (CEPQM) at Boston Children's Hospital

Members of CEPQM's Scientific Advisory Board and National Stakeholder Panel

Members of the Massachusetts Child Health Quality Coalition

Members of the Boston Children's Hospital Teen Advisory Council

We thank the participants in our focus groups, cognitive interviews, and field tests and all others who contributed to the development and testing of the ADAPT survey.

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Appendix A: ADAPT surveys (Health Plan and Clinical Program versions, English)

ADAPT survey: Health Plan

YOUR EXPERIENCES GETTING HEALTH CARE

INSTRUCTIONS

Answer all the questions by checking the box next to your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

- Yes → **If Yes, go to #1**
 No

Your participation is voluntary. You may choose to answer the survey or not. If you choose not to, this will not affect the health care you get.

What to do when you're done. Please return the completed survey in the postage paid envelope.

1. Your **main** provider is the doctor or other health care provider who is in charge of the care for your health condition. If you have more than one health condition, please think about the condition that concerns you the most.

Which of the providers named below is your **main** provider?

Paste label here with up to 3 provider names

- None of these are my main provider, my main provider is _____
(please print)

The questions in this survey will refer to the provider chosen in question 1 as "this provider." Please think of that provider as you answer the survey.

2. How long have you been going to this provider?
- Less than 6 months
 At least 6 months but less than 1 year
 At least 1 year but less than 3 years
 At least 3 years but less than 5 years
 5 years or more

3. In the last 12 months, how many times did you visit this provider?

- None → **If None, go to #19**
 1 time
 2
 3
 4
 5 to 9
 10 or more times

4. In the last 12 months, did you talk with this provider without your parent or guardian in the room?

- Yes
 No

5. In the last 12 months, did you and this provider talk about **you** being more in charge of your health?

- Yes
 No

6. In the last 12 months, did you and this provider talk about **you** scheduling your own appointments with this provider instead of your parent or guardian?

- Yes
 No

7. In the last 12 months, how often did you schedule your own appointments with this provider?

- Never
- Sometimes
- Usually
- Always

8. In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?

- Yes
- No

Your Prescription Medicines

9. In the last 12 months, did you take any prescription medicine?

- Yes → If Yes, go to #10
- No → If No, go to #14

10. In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?

- Never
- Sometimes
- Usually
- Always

11. In the last 12 months, were you prescribed any medicine to take every day for at least a month?

- Yes → If Yes, go to #12
- No → If No, go to #14

12. In the last 12 months, did you and this provider talk about remembering to take your medicines?

- Yes
- No

13. In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?

- Yes
- No

Your Provider

14. Does this provider treat mostly children and teens?

- Yes → If Yes, go to #15
- No → If No, go to #19
- Don't Know → If Don't Know, go to #15

15. In the last 12 months, did you and this provider talk about whether you may need to change to a new provider who treats mostly adults?

- Yes → If Yes, go to #16
- No → If No, go to #19

16. In the last 12 months, did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults?

- Yes
- No

17. In the last 12 months, did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults?

- Yes → If Yes, go to #18
- No → If No, go to #19

18. Did this provider give you this plan in writing?

- Yes
- No

About You

19. How old are you?

- 15
- 16
- 17
- 18

20. Are you male or female?

- Male
- Female

21. In general, how would you rate your overall health?

- Excellent
- Very good
- Good
- Fair
- Poor

22. What is the highest grade or level of school that you have completed?

- 8th grade or less
- 9th grade
- 10th grade
- 11th grade
- 12th grade, high school graduate or GED
- Some college

23. Are you of Hispanic, Latino, or Spanish origin? Mark one or more.

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin

24. How would you describe your race?**Mark one or more.**

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander

- American Indian or Alaska Native

25. Did someone help you complete this survey?

- Yes → **If Yes, go to #26**
- No → Thank you. Please return the completed survey in the postage-paid envelope.

26. How did that person help you?**Mark one or more.**

- Read the questions to me
- Wrote down the answers I gave
- Answered the questions for me
- Translated the questions into my language
- Helped in some other way: _____

Please print

Thank you.

Please return the survey in the postage-paid envelope.

INSTRUCTIONS

Answer all the questions by checking the box next to your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

- Yes → **If Yes, go to #1**
 No

Your participation is voluntary. You may choose to answer the survey or not. If you choose not to, this will not affect the health care you get.

What to do when you're done. Please return the completed survey in the postage paid envelope.

1. Your **main** provider is the doctor or other health care provider who is in charge of the care for your health condition. If you have more than one health condition, please think about the condition that concerns you the most.

Is the provider named below your **main** provider?

Paste label here with provider name

- Yes
 No, my main provider is _____
(please print)

The questions in this survey will refer to the provider chosen in question 1 as "this provider." Please think of that provider as you answer the survey.

2. How long have you been going to this provider?
- Less than 6 months
 At least 6 months but less than 1 year
 At least 1 year but less than 3 years
 At least 3 years but less than 5 years
 5 years or more

3. In the last 12 months, how many times did you visit this provider?

- None → **If None, go to #19**
 1 time
 2
 3
 4
 5 to 9
 10 or more times

4. In the last 12 months, did you talk with this provider without your parent or guardian in the room?

- Yes
 No

5. In the last 12 months, did you and this provider talk about **you** being more in charge of your health?

- Yes
 No

6. In the last 12 months, did you and this provider talk about **you** scheduling your own appointments with this provider instead of your parent or guardian?

- Yes
 No

7. In the last 12 months, how often did you schedule your own appointments with this provider?

- Never
- Sometimes
- Usually
- Always

8. In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?

- Yes
- No

Your Prescription Medicines

9. In the last 12 months, did you take any prescription medicine?

- Yes → If Yes, go to #10
- No → If No, go to #14

10. In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?

- Never
- Sometimes
- Usually
- Always

11. In the last 12 months, were you prescribed any medicine to take every day for at least a month?

- Yes → If Yes, go to #12
- No → If No, go to #14

12. In the last 12 months, did you and this provider talk about remembering to take your medicines?

- Yes
- No

13. In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?

- Yes
- No

Your Provider

14. Does this provider treat mostly children and teens?

- Yes → If Yes, go to #15
- No → If No, go to #19
- Don't Know → If Don't Know, go to #15

15. In the last 12 months, did you and this provider talk about whether you may need to change to a new provider who treats mostly adults?

- Yes → If Yes, go to #16
- No → If No, go to #19

16. In the last 12 months, did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults?

- Yes
- No

17. In the last 12 months, did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults?

- Yes → If Yes, go to #18
- No → If No, go to #19

18. Did this provider give you this plan in writing?

- Yes
- No

About You

19. How old are you?

- 15
- 16
- 17
- 18

20. Are you male or female?

- Male
- Female

21. In general, how would you rate your overall health?

- Excellent
- Very good
- Good
- Fair
- Poor

22. What is the highest grade or level of school that you have completed?

- 8th grade or less
- 9th grade
- 10th grade
- 11th grade
- 12th grade, high school graduate or GED
- Some college

23. Are you of Hispanic, Latino, or Spanish origin? Mark one or more.

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin

24. How would you describe your race?**Mark one or more.**

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native

25. Did someone help you complete this survey?

- Yes → **If Yes, go to #26**
- No → Thank you. Please return the completed survey in the postage-paid envelope.

26. How did that person help you?**Mark one or more.**

- Read the questions to me
- Wrote down the answers I gave
- Answered the questions for me
- Translated the questions into my language
- Helped in some other way: _____

Please print

Thank you.

Please return the survey in the
postage-paid envelope.

INSTRUCCIONES

Contesta todas las preguntas marcando el cuadrado junto a la respuesta que desees escoger. A veces en la encuesta te dicen que saltes algunas preguntas. Cuando esto suceda, verás una flecha con una nota que dice cuál pregunta debes contestar a continuación, como se muestra abajo:

- Sí → **Si contestas Sí, pasa a la pregunta 1**
 No

Tu participación es voluntaria. Puedes decidir si vas a contestar la encuesta o no. Aunque decidas no contestarla, la atención médica que recibes no se verá afectada.

Qué hacer cuando termines de contestarla. Por favor envíanos la encuesta completada en el sobre con porte o franqueo pagado.

1. Tu proveedor principal es el doctor u otro profesional médico que está a cargo de la atención médica por tu problema de salud. Si tienes más de un problema de salud, por favor piensa en el problema que más te preocupa.

¿Cuál de los proveedores mencionados a continuación es tu proveedor principal?

Paste label here with up to 3 provider names

- Ninguno de estos es mi proveedor principal; mi proveedor principal es _____
(en letra de imprenta o de molde)

Cuando las preguntas en esta encuesta dicen "este proveedor" se están refiriendo al proveedor que elegiste en la pregunta 1. Por favor piensa en ese proveedor cuando contestes la encuesta.

2. ¿Cuánto tiempo hace que estás yendo a este proveedor?
- Menos de 6 meses
 - Al menos 6 meses pero menos de 1 año
 - Al menos 1 año pero menos de 3 años
 - Al menos 3 años pero menos de 5 años
 - 5 años o más

3. En los últimos 12 meses, ¿cuántas veces visitaste a este proveedor?

- Ninguna → **Si contestas Ninguna, pasa a la pregunta 19**
- 1 vez
 - 2
 - 3
 - 4
 - 5 a 9
 - 10 o más veces

4. En los últimos 12 meses, ¿hablaste con este proveedor a solas, sin que uno de tus padres o tutores estuviera en el consultorio?

- Sí
 No

5. En los últimos 12 meses, ¿habló contigo este proveedor acerca de que tú estuvieras más a cargo de tu salud?

- Sí
 No

6. En los últimos 12 meses, ¿habló contigo este proveedor acerca de que tú hicieras tus propias citas con este proveedor en vez de que las hicieran tus padres o tutores?

- Sí
 No

7. En los últimos 12 meses, ¿qué tan seguido hiciste tú mismo(a) tus citas con este proveedor?

- Nunca
- Algunas veces
- Generalmente
- Siempre

8. En los últimos 12 meses, ¿habló este proveedor contigo acerca de que tal vez tengas que cambiar de seguro de salud cuando seas mayor?

- Sí
- No

Tus medicinas recetadas

9. En los últimos 12 meses, ¿tomaste alguna medicina recetada?

- Sí → Si contestas Sí, pasa a la pregunta 10
- No → Si contestas No, pasa a la pregunta 14

10. En los últimos 12 meses, ¿qué tan seguido habló este proveedor contigo en cada visita acerca de todas tus medicinas recetadas?

- Nunca
- Algunas veces
- Generalmente
- Siempre

11. En los últimos 12 meses, ¿te recetaron alguna medicina para tomar todos los días por al menos un mes?

- Sí → Si contestas Sí, pasa a la pregunta 12
- No → Si contestas No, pasa a la pregunta 14

12. En los últimos 12 meses, ¿habló este proveedor contigo acerca de acordarte de tomar tus medicinas?

- Sí
- No

13. En los últimos 12 meses, ¿habló este proveedor contigo acerca de que tú hagas surtir tus medicinas recetadas en vez de tus padres o tutores?

- Sí
- No

Tu proveedor

14. ¿Este proveedor trata principalmente a niños y adolescentes?

- Sí → Si contestas Sí, pasa a la pregunta 15
- No → Si contestas No, pasa a la pregunta 19
- No sé → Si contestas No sé, pasa a la pregunta 15

15. En los últimos 12 meses, ¿habló este proveedor contigo acerca de si podrías necesitar cambiarte a un proveedor nuevo que trate principalmente a adultos?

- Sí → Si contestas Sí, pasa a la pregunta 16
- No → Si contestas No, pasa a la pregunta 19

16. En los últimos 12 meses, ¿te preguntó este proveedor si tenías alguna pregunta o inquietud acerca de cambiarte a un proveedor nuevo que trate principalmente a adultos?

- Sí
- No

17. En los últimos 12 meses, ¿habló este proveedor contigo acerca de un plan específico para cambiarte a un proveedor nuevo que atiende principalmente a adultos?

- Sí → Si contestas Sí, pasa a la pregunta 18
- No → Si contestas No, pasa a la pregunta 19

18. ¿Te dio este proveedor el plan por escrito?

- Sí
- No

Acerca de ti**19. ¿Cuántos años tienes?**

- 15
- 16
- 17
- 18

20. ¿Eres hombre o mujer?

- Hombre
- Mujer

21. En general, ¿cómo calificarías toda tu salud?

- Excelente
- Muy buena
- Buena
- Regular
- Mala

22. ¿Cuál es el grado o nivel escolar más alto que has completado?

- 8 años de escuela o menos
- 9 años de escuela
- 10 años de escuela
- 11 años de escuela
- 12 años de escuela, graduado de *high school*, diploma de *high school*, preparatoria, o su equivalente (o GED)
- Algunos cursos de *college* o universidad

23. ¿Eres de origen hispano, latino o español?**Marca todas las opciones que correspondan.**

- No, ni de origen hispano, ni latino, ni español
- Sí, de origen mexicano, mexicano-americano, chicano
- Sí, de origen puertorriqueño
- Sí, de origen cubano
- Sí, de otro origen hispano, latino o español

24. ¿Cómo describirías tu raza?**Marca todas las opciones que correspondan.**

- Blanca
- Negra o afroamericana
- Asiática
- Nativa de Hawái o de otras islas del Pacífico
- Indígena americana o nativa de Alaska

25. ¿Te ayudó alguien a contestar esta encuesta?

- Sí → **Si contestaste Sí, pasa a la pregunta 26**
- No → Gracias. Por favor, devuelve esta encuesta en el sobre con el porte o franqueo pagado.

26. ¿Cómo te ayudó esta persona?**Marca todas las opciones que correspondan.**

- Me leyó las preguntas.
- Anotó las respuestas que le di.
- Contestó las preguntas por mí.
- Tradujo las preguntas a mi idioma.
- Me ayudó de otra forma: _____

Escribe de qué forma te ayudó

Muchas Gracias.

Por favor envíanos la encuesta en el sobre con porte o franqueo pagado.

INSTRUCCIONES

Contesta todas las preguntas marcando el cuadrado junto a la respuesta que desees escoger.

A veces en la encuesta te dicen que saltes algunas preguntas. Cuando esto suceda, verás una flecha con una nota que dice cuál pregunta debes contestar a continuación, como se muestra abajo:

- Sí → **Si contestas Sí, pasa a la pregunta 1**
 No

Tu participación es voluntaria. Puedes decidir si vas a contestar la encuesta o no. Aunque decidas no contestarla, la atención médica que recibes no se verá afectada.

Qué hacer cuando termines de contestarla. Por favor envíanos la encuesta completada en el sobre con porte o franqueo pagado.

1. Tu proveedor **principal** es el doctor u otro profesional médico que está a cargo de la atención médica por tu problema de salud. Si tienes más de un problema de salud, por favor piensa en el problema que más te preocupa.

¿El proveedor que aparece a continuación es tu proveedor principal?

Paste label here with provider name

- Sí
 No, mi proveedor principal es _____

(en letra de imprenta o de molde)

Cuando las preguntas en esta encuesta dicen "este proveedor" se están refiriendo al proveedor que elegiste en la pregunta 1. Por favor piensa en ese proveedor cuando contestes la encuesta.

2. ¿Cuánto tiempo hace que estás yendo a este proveedor?
- Menos de 6 meses
 Al menos 6 meses pero menos de 1 año
 Al menos 1 año pero menos de 3 años
 Al menos 3 años pero menos de 5 años
 5 años o más

3. En los últimos 12 meses, ¿cuántas veces visitaste a este proveedor?

- Ninguna → **Si contestas Ninguna, pasa a la pregunta 19**
 1 vez
 2
 3
 4
 5 a 9
 10 o más veces

4. En los últimos 12 meses, ¿hablaste con este proveedor a solas, sin que uno de tus padres o tutores estuviera en el consultorio?

- Sí
 No

5. En los últimos 12 meses, ¿habló contigo este proveedor acerca de que **tú** estuvieras más a cargo de tu salud?

- Sí
 No

6. En los últimos 12 meses, ¿habló contigo este proveedor acerca de que **tú** hicieras tus propias citas con este proveedor en vez de que las hicieran tus padres o tutores?

- Sí
 No

7. En los últimos 12 meses, ¿qué tan seguido hiciste tú mismo(a) tus citas con este proveedor?

- Nunca
- Algunas veces
- Generalmente
- Siempre

8. En los últimos 12 meses, ¿habló este proveedor contigo acerca de que tal vez tengas que cambiar de seguro de salud cuando seas mayor?

- Sí
- No

Tus medicinas recetadas

9. En los últimos 12 meses, ¿tomaste alguna medicina recetada?

- Sí → Si contestas Sí, pasa a la pregunta 10
- No → Si contestas No, pasa a la pregunta 14

10. En los últimos 12 meses, ¿qué tan seguido habló este proveedor contigo en cada visita acerca de todas tus medicinas recetadas?

- Nunca
- Algunas veces
- Generalmente
- Siempre

11. En los últimos 12 meses, ¿te recetaron alguna medicina para tomar todos los días por al menos un mes?

- Sí → Si contestas Sí, pasa a la pregunta 12
- No → Si contestas No, pasa a la pregunta 14

12. En los últimos 12 meses, ¿habló este proveedor contigo acerca de acordarte de tomar tus medicinas?

- Sí
- No

13. En los últimos 12 meses, ¿habló este proveedor contigo acerca de que tú hagas surtir tus medicinas recetadas en vez de tus padres o tutores?

- Sí
- No

Tu proveedor

14. ¿Este proveedor trata principalmente a niños y adolescentes?

- Sí → Si contestas Sí, pasa a la pregunta 15
- No → Si contestas No, pasa a la pregunta 19
- No sé → Si contestas No sé, pasa a la pregunta 15

15. En los últimos 12 meses, ¿habló este proveedor contigo acerca de si podrías necesitar cambiarte a un proveedor nuevo que trate principalmente a adultos?

- Sí → Si contestas Sí, pasa a la pregunta 16
- No → Si contestas No, pasa a la pregunta 19

16. En los últimos 12 meses, ¿te preguntó este proveedor si tenías alguna pregunta o inquietud acerca de cambiarte a un proveedor nuevo que trate principalmente a adultos?

- Sí
- No

17. En los últimos 12 meses, ¿habló este proveedor contigo acerca de un plan específico para cambiarte a un proveedor nuevo que atiende principalmente a adultos?

- Sí → Si contestas Sí, pasa a la pregunta 18
- No → Si contestas No, pasa a la pregunta 19

18. ¿Te dio este proveedor el plan por escrito?

- Sí
- No

Acerca de ti**19. ¿Cuántos años tienes?**

- 15
- 16
- 17
- 18

20. ¿Eres hombre o mujer?

- Hombre
- Mujer

21. En general, ¿cómo calificarías toda tu salud?

- Excelente
- Muy buena
- Buena
- Regular
- Mala

22. ¿Cuál es el grado o nivel escolar más alto que has completado?

- 8 años de escuela o menos
- 9 años de escuela
- 10 años de escuela
- 11 años de escuela
- 12 años de escuela, graduado de *high school*, diploma de *high school*, preparatoria, o su equivalente (o GED)
- Algunos cursos de *college* o universidad

23. ¿Eres de origen hispano, latino o español?**Marca todas las opciones que correspondan.**

- No, ni de origen hispano, ni latino, ni español
- Sí, de origen mexicano, mexicano-americano, chicano
- Sí, de origen puertorriqueño
- Sí, de origen cubano
- Sí, de otro origen hispano, latino o español

24. ¿Cómo describirías tu raza?**Marca todas las opciones que correspondan.**

- Blanca
- Negra o afroamericana
- Asiática
- Nativa de Hawái o de otras islas del Pacífico
- Indígena americana o nativa de Alaska

25. ¿Te ayudó alguien a contestar esta encuesta?

- Sí → **Si contestaste Sí, pasa a la pregunta 26**
- No → Gracias. Por favor, devuelve esta encuesta en el sobre con el porte o franqueo pagado.

26. ¿Cómo te ayudó esta persona?**Marca todas las opciones que correspondan.**

- Me leyó las preguntas.
- Anotó las respuestas que le di.
- Contestó las preguntas por mí.
- Tradujo las preguntas a mi idioma.
- Me ayudó de otra forma: _____

*Escribe de qué forma te ayudó***Muchas Gracias.****Por favor envíanos la encuesta en el sobre con porte o franqueo pagado.**

Appendix C: English mailed survey materials

Cover letter for initial mailing

Parent or Guardian of [name of child]
Address
City, State, Zip

Dear Parent or Guardian of [name of child]:

You received this survey because your child is 16 or 17 years old and has seen a health care provider in the last 12 months. We are sending this survey to measure the quality of care that your child has received from this provider. We would like you to give your child the attached survey to fill out.

This survey is voluntary. If you allow your child to answer the survey, please give it to them to complete. This survey should take 10 minutes or less. If possible, we would like your child to answer the survey on their own. However, it is ok if they need some help from you, for example, to read the questions or to write down the answers for them.

If your child is not able to understand the questions in this survey and answer them at all, please do not answer for them. Please check the box below and return this letter and the survey without completing it. Please do not answer for them.

My child is not able to answer the survey.

Your child may choose not to answer this survey. This will not affect their medical care in any way.

The information that your child provides will be kept completely private and confidential. Answers will not be matched with your child's name. Their individual answers will never be seen by their provider or anyone else involved with their care. When your child has completed the survey, please mail it back in the envelope that came with it. No postage is needed.

If you have any questions about this survey, please call XX XXX at XXX-XXX.

Sincerely,

XXX XXXX MD

Cover letter for second mailing

Parent or Guardian of [name of child]

Address

City, State, Zip

Dear Parent or Guardian of [name of child]:

About [number of weeks/days] ago, we sent you a survey to give to your child. You received this survey because your child is 16 or 17 years old and has seen a health care provider in the last 12 months. We are sending this survey to measure the quality of care that your child has received from this provider. We would like you to give your child the attached survey to fill out. If your child has already returned the survey to us, please accept our thanks and ignore this letter.

This survey is voluntary. If you allow your child to answer the survey, please give it to them to complete. This survey should take 10 minutes or less. If possible, we would like your child to answer the survey on their own. However, it is ok if they need some help from you, for example, to read the questions or to write down the answers for them.

If your child is not able to understand the questions in this survey and answer them at all, please do not answer for them. Please check the box below and return this letter and the survey without completing it. Please do not answer for them.

My child is not able to answer the survey.

Your child may choose not to answer this survey. This will not affect their medical care in any way.

The information that your child provides will be kept completely private and confidential. Answers will not be matched with your child's name. Their individual answers will never be seen by their provider or anyone else involved with their care. When your child has completed the survey, please mail it back in the envelope that came with it. No postage is needed.

If you have any questions about this survey, please call XX XXX at XXX-XXX.

Sincerely,

XXX XXXX MD

Appendix D: Spanish mailed survey materials

Cover letter for initial mailing

Padre/Madre o Tutor/Guardián Legal de [name of child]
 Dirección
 Ciudad, Estado, Código Postal

Estimado padre, madre, o tutor/guardián legal de [name of child]:

Usted recibió esta encuesta porque su hijo(a) tiene 16 o 17 años y ha visitado a un proveedor de atención médica en los últimos 12 meses. Enviamos esta encuesta para medir la calidad de atención médica que su hijo ha recibido de este proveedor. Nos gustaría que le entregue a su hijo(a) la encuesta que viene incluida para que la complete.

Esta encuesta es voluntaria. Si usted le da permiso a su hijo(a) para que conteste la encuesta, por favor entréguesela para que la complete. Completar la encuesta deberá tomar unos 10 minutos o menos. Si es posible, nos gustaría que su hijo(a) sea quien conteste las preguntas por su cuenta. Sin embargo, si él/ella necesita algo de su ayuda, por ejemplo, que usted le lea las preguntas o le escriba sus respuestas, usted puede hacerlo.

Si su hijo(a) no puede entender las preguntas de esta encuesta y no puede contestarlas en absoluto, por favor no las conteste usted en nombre de él/ella. Por favor marque el cuadrado que está a continuación y devuelva esta carta y la encuesta sin completar.

Mi hijo(a) no puede contestar la encuesta.

Su hijo(a) puede decidir no contestar esta encuesta. Esa decisión no tendrá ningún efecto en absoluto en su atención médica.

La información que su hijo(a) proporcione se mantendrá de manera totalmente privada y confidencial. Las respuestas no serán asociadas con el nombre de su hijo(a). Sus respuestas individuales nunca serán vistas por su proveedor de atención médica o por alguien más que esté involucrado con su atención médica. Cuando su hijo(a) haya completado la encuesta, por favor envíela por correo en el sobre que le enviamos con la encuesta. . No hace falta poner sellos postales.

Si tiene preguntas acerca de esta encuesta, por favor llame a XX XXX al teléfono XXX-XXXX. Este es un teléfono gratuito.

Le saluda atentamente,

xxxxxxxx, MD

Cover letter for second mailing

Padre/Madre o Tutor/Guardián Legal de [name of child]

Dirección

Ciudad, Estado, Código Postal

Estimado padre, madre, o tutor/guardián legal de [name of child]:

Aproximadamente [number of weeks/days] (semanas/días) atrás le enviamos una encuesta para su hijo(a). Usted recibió esta encuesta porque su hijo(a) tiene 16 o 17 años y ha visitado a un proveedor de atención médica en los últimos 12 meses. Enviamos esta encuesta para medir la calidad de atención médica que su hijo ha recibido de este proveedor. Nos gustaría que le entregue a su hijo(a) la encuesta que viene incluida para que la complete. Si su hijo(a) ya nos ha enviado la encuesta, le estamos muy agradecidos y usted puede ignorar esta carta.

Esta encuesta es voluntaria. Si usted le da permiso a su hijo(a) para que conteste la encuesta, por favor entréguesela para que la complete. Completar la encuesta deberá tomar unos 10 minutos o menos. Si es posible, nos gustaría que su hijo(a) sea quien conteste las preguntas por su cuenta. Sin embargo, si él/ella necesita algo de ayuda, por ejemplo, que usted le lea las preguntas o escriba sus respuestas, usted puede hacerlo.

Si su hijo(a) no puede entender las preguntas de esta encuesta y no puede contestarlas del todo, por favor no las conteste usted en nombre de él/ella. Por favor marque el cuadro que está a continuación y devuelva esta carta y la encuesta sin completar.

Mi hijo(a) no puede contestar la encuesta.

Su hijo(a) puede decidir no contestar la encuesta. Esa decisión no tendrá ningún efecto en absoluto en su atención médica.

La información que su hijo(a) proporcione se mantendrá de manera totalmente privada y confidencial. Las respuestas no serán asociadas con el nombre de su hijo(a). Sus respuestas individuales nunca serán vistas por otro proveedor de atención médica o por alguien más que esté involucrado en su atención médica. Cuando su hijo(a) haya completado la encuesta, por favor envíela por correo en el sobre que le enviamos junto con la encuesta. No hace falta poner sellos postales.

Si tiene preguntas acerca de esta encuesta, por favor llame a XX XXX al teléfono XXX-XXXX. Este es un número de teléfono gratuito.

Le saluda atentamente,

xxxxxxxx, MD

Appendix E: Decision rules and coding guidelines

To ensure accurate collection of all survey data, quality control procedures should be developed, implemented, and documented for all survey administration activities. The ADAPT survey decision rules and coding guidelines were developed to capture appropriate information for data submission. They provide guidance for addressing situations in which survey responses are ambiguous, missing or incorrectly provided. Adherence to the following decision rules and coding guidelines should ensure valid and consistent coding of such instances.

Multiple returned surveys from the same respondent

If health plans, practices, hospitals, or survey vendors administer the ADAPT survey using a multiple-wave mail protocol, it is possible for a respondent to receive, complete and return multiple surveys. When multiple surveys from the same respondent are received, code the first returned completed survey.

Coding ambiguous responses

A common problem in mailed surveys is ambiguity of responses on returned surveys. To ensure uniformity in data coding, strictly apply the following guidelines. When scanning or key-entering paper-based surveys, use the following decision rules for resolving common ambiguous situations:

- If a value is missing, then code the value as “. Missing.” A response should not be imputed; in other words, do not try to determine what the respondent would have responded for the missing value based on answers to other questions. Except
- If a mark falls between two response options but is obviously closer to one than the other, then select the choice to which the mark is closest.
- If a mark falls equidistant between two response options, then code the value as “. Missing”.
- If more than one response option is marked for Questions 4, 5, 6, 8, 12, 13, 16, 18, and 20, i.e. both yes and no are marked, code the value as “. Missing.”
- If more than one response option is marked for Questions 2, 3, 7, 10, 19, 21, and 22, code the option that represents the highest level of value to this question, e.g., higher level of school completed or more frequent visits.
- There are seven screener questions in this survey (Questions 3, 9, 11, 14, 15, 17, and 25). When more than one response option is marked for any of the screener questions, the decision of which option to code depends on how the associated dependent question(s) is answered:
 - If the associated dependent question(s) is answered, code the option of the screener question that allows the dependent question(s) to be answered.
 - If the associated dependent question(s) is not answered, code the option of the screener questions that allows the dependent question(s) to be skipped.
 - Exception: for Question 14, “Does this provider treat mostly children and teens?”, if more than one option is marked, code “Don’t know”.

In instances in which multiple options are marked **but** the respondent’s intent is clear, code the respondent’s **clearly identified** intended response.

For question 23 “Are you of Hispanic, Latino, or Spanish origin? Mark one or more,” and question 24 “How would you describe your race? Mark one or more,” enter responses for all of the categories that the respondent has selected.

Skip patterns

Several items in the ADAPT survey can and should be skipped by certain respondents. These items form skip patterns. Seven questions in the ADAPT survey serve as screener questions (Questions 3, 9, 11, 14, 15, 17, and 25) that determine whether the associated dependent questions should be answered. The following decision rules are provided to assist in coding responses to skip pattern questions.

Decision Rules for Screener and Dependent Questions

Decision rules for coding **screener questions** (Questions 3, 9, 11, 14, 15, 17, and 25):

- Enter the value provided by the respondent. Do not impute a response based on the respondent’s answers to the dependent questions.
- If a screener question is left blank, then code the value as “. Missing.” Do not impute a response based on the respondent’s answers to the dependent questions.
- In the situation where more than one option is marked for a screener question, see rules in the “Coding Ambiguous Responses” section.

Decision rules for coding **dependent questions** (Questions 4-18, and 26):

- If the marked screener question option requires the dependent question(s) to be answered, and the dependent question(s) is left blank, then code the value for the dependent question(s) as “. Missing.”
- If the marked screener question option requires the dependent question(s) to be answered, and the dependent question(s) is **not** left blank, then enter the value provided by the respondent for the dependent question(s).
- If the marked screener question option requires the dependent question(s) to be skipped, and the dependent question(s) is left blank, then code the value for the dependent question(s) as “. Missing.”
- If the marked screener question option requires the dependent question(s) to be skipped, and the dependent question(s) is **not** left blank, then code the value for the dependent question(s) as “. Missing.”
- If the screener question is left blank and the dependent question(s) is left blank, then code the value for both the corresponding screener question and the dependent question(s) as “. Missing.”
- If the screener question is left blank and the dependent question(s) is **not** left blank, then code the value for the corresponding screener question as “. Missing” and enter the value provided by the respondent for the dependent question(s).

Recoding and collapsing variables

In instances in which some variables need to be recoded or collapsed for analysis or reporting, the following rules can be used.

Collapsing **Race and Ethnicity** from Question 23 (Are you of Hispanic, Latino, or Spanish origin? Mark one or more) and Question 24 (How would you describe your race? Mark one or more):

- If Question 23 is marked “Yes”, including “Yes, Mexican, Mexican American, Chicano”, “Yes, Puerto Rican,” “Yes, Cuban,” or “Yes, another Hispanic, Latino, or Spanish origin”, code the respondent as “Hispanic” regardless of what race(s) is marked.
- If Question 23 is marked “No, not of Hispanic, Latino, or Spanish origin” and only one option of Question 24 is marked, code the respondent as their marked race, for example “White Non-Hispanic”, “Black Non-Hispanic”, “American Indian or Alaska Native Non-Hispanic.”
- If Question 23 is marked “No, not of Hispanic, Latino, or Spanish origin” and multiple races are marked for Question 23, code the respondent as “Multi-Racial.”

Recoding **Help Received to Complete this Survey** from Question 26 (How did that person help you? Mark one or more):

- If only one option is marked for Question 26, code the recoded variable as their marked level of help, for example “Read the questions only”, “Wrote the answers only”, “Helped in some other way only.”
- If multiple options are marked for Question 26, code the recoded variable as “Helped in multiple ways.”

Am I ON TRAC? For Adult Care Questionnaire
A Youth Readiness Questionnaire for Youth 12-19 years of age
Youth Version of Questionnaire

Developed by BC Children's Hospital
ON TRAC Transition Initiative

Validated in partnership with UBC School of Nursing

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For validation study of AM I ON TRAC Youth Readiness Questionnaire

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For opportunities for collaborative testing of this tool or other ON TRAC tools, BC's Children's Hospital

Research Team Members:

Melissa Moynihan, MSN, RN, UBC School of Nursing
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This questionnaire has been designed to be used every year, or every few years, with adolescents who have chronic health conditions and/ or disabilities, to assess their progress towards readiness to transition to adult health care services. Instructions for how to score it are on the page following the questionnaire. While the instrument is available for use for free, we would appreciate being informed should you choose to use it, so that we can track its usefulness, and so we can inform you of any refinements or enhanced versions as they become available.

Suggested citation for the tool itself:

Paone M., Moynihan M., Whitehouse S., Saewyc E. (2012). Am I ON TRAC for Adult Care? Youth readiness questionnaire, 2012 version. British Columbia Children's Hospital, Vancouver, BC, Canada.

Suggested citation for validation:

Moynihan, M., Saewyc, E., Whitehouse, S., Paone, M., & McPherson, G. Assessing readiness for transition from paediatric to adult health care: Revision and psychometric evaluation of the Am I ON TRAC for Adult Care Questionnaire. *Journal of Advanced Nursing*, 71(6), 1324-1355. DOI: 10.1111/jan.12617

For updated information on readiness tools and testing visit Projects section – www.ontrac.bc.ca

AM I ON TRAC – For Adult Care Questionnaire (Version January 2012)
 Youth Readiness Questionnaire

For each of the following statements select the response that best describes you

Knowledge Indicators	Strongly disagree	Disagree	Agree	Strongly agree
1. I can describe my health condition to others				
2. I know what my long-term health problems might be				
3. I know what patient confidentiality means				
4. I understand the risks and benefits of health care treatments before consenting to those treatments				
5. I know how to get my medical records				
6. I know the names of my medications				
7. I know what each of my medications are for				
8. I know the side effects of the medications I take				
9. I can get to my clinic appointments on my own				
10. I know how my condition might affect my sexual health				
11. I know how to prevent sexual health risks such as pregnancy and sexually transmitted infections (STIs)				
12. I know how my health condition might limit my career choices				
13. I know how my health condition affects my physical activities				
14. I know how alcohol, drugs and tobacco can affect my medications				
15. I have a family doctor				
16. My family supports me in managing my health				

Behavioral Indicators	Never	Rarely	Sometimes	Often	Always
17. I visit my family doctor when I need to (For example: to have check-ups, get birth control, or if I have the flu)					
18. I meet with my health care providers on my own					
19. I participate in clubs, groups, sports or activities					
20. I talk to my friend(s) about my problems or worries					
21. I participate in activities/exercise to stay healthy					
22. I ask health care providers questions about my health at my visits					
23. I take my medications on my own					
24. When my symptoms are getting worse I contact the clinic for help					
25. I think about what I would like to do after high school					



**Scoring Guide for Revised
Am I ON TRAC for Adult Care Questionnaire (January 2012)
Youth Version**

Knowledge Scale - Items 1 to 14 (items 15 and 16 are not part of the scale, but separate indicators)

Scoring: Strongly disagree = 1 Disagree = 2, Agree = 3, Strongly agree = 4

Items 15 and 16 are not included in the score.

Sum item scores. Scores range from 14 to 56.

*If youth indicate they are not taking any medications items 6, 7, and 8 are not scored.

Scores range from 11 to 44.

Behaviour Index – Items 17 to 25

Scoring: Never = 1, Rarely = 2, Sometimes = 3, Often = 4, Always = 5

Raw Score - sum item scores. Scores range from 9 to 45

*If youth indicate they are not taking any medications item 23 is not scored. Scores range from 8 to 40.

Behaviour Cut-off Score – items 17 to 25 are given a 0 if threshold is not met and a 1 if the threshold is met. Item thresholds:

Question 17 – Often or higher

Question 18 – Sometimes or higher

Question 19 – Sometimes or higher

Question 20 – Sometimes or higher

Question 21 – Sometimes or higher

Question 22 – Often or higher

Question 23 – Often or higher

Question 24 – Often or higher

Question 25 – Often or higher

Threshold scores are summed. Youth need a cut-off score of at least 8 or 9 to be deemed ready for transition to adult care.

* If youth indicate they are not taking any medications item 23 is not scored and youth need a cut-off score of at least 7 or 8 to be deemed ready for transition to adult care.

Getting Ready to Leave: Transition Readiness in Adolescent Kidney Transplant Recipients

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Received January 8, 2011; revisions received and accepted June 14, 2011

Objective To develop a measure of transition readiness and assess factors associated with perceived readiness for transition of healthcare responsibility and transfer among adolescent kidney transplant recipients. **Methods** The Readiness for Transition Questionnaire (RTQ-teen; RTQ-parent) was created to assess overall transition readiness, adolescent healthcare behavior, and familial involvement in healthcare. Participants were 48 adolescent kidney transplant recipients ages 15–21 years. Thirty-two (66.7%) of the adolescents' caregivers also participated. Adolescents completed the RTQ-teen, as well as self-reported measures of adherence and barriers to adherence. Parents completed the RTQ-parent. **Results** The RTQ showed good internal consistency, inter rater reliability, and demonstrated construct validity. Increased adolescent responsibility and decreased parental involvement predicted higher transition readiness. Additionally, greater adolescent adherence factors predicted greater transition readiness. **Conclusions** The preliminary psychometrics of the RTQ appear to be supported. Additional research should evaluate healthcare transition programming to identify clinical components related to improved transition readiness, adolescent responsibility, and medical outcomes.

Key words adolescent; healthcare responsibility; transition; transplant.

Introduction

Pediatric transplant recipients are living longer due to improved immunosuppression regimens and better allograft survival, with many of these patients surviving well into adulthood. In the past decade, the number of adolescent kidney transplants has increased 35% (Magee, Krishnan, Benfield, Hsu, & Shneider, 2008). The transition from pediatric to adult medical care is thus a growing area of clinical concern for transplant recipients and healthcare providers. Transition has been conceptualized as both a process and an event (Annunziato et al., 2007; Rodrigue & Zelikovsky, 2009). The process (i.e., transition) necessitates gradual, increased healthcare responsibility being turned over from the parent to the adolescent, while the event (i.e., transfer) occurs when the patient transfers from a pediatric to an adult healthcare team. Although transition is a prominent issue in healthcare, the available literature

on healthcare transition is in its infancy, and the need for empirical and intervention research in this area is crucial. Transfer to adult centered care has been associated with a 30% allograft loss in kidney transplant patients 15-months posttransfer (Watson, 2000) and with increased nonadherence, lower serum immunosuppressant levels, and increased mortality in liver transplant recipients (Annunziato et al., 2007). Progress in transition research has been limited, in part, due to the lack of psychometrically valid measures. The current investigation addresses this deficit by evaluating a measure of transition readiness that assesses shifts in healthcare responsibility from parents to adolescent participants in a transitional program for adolescent kidney transplant recipients.

In a systematic review of transitional care research, While et al. (2004) proposed four theoretical practice models for pediatric transition to adult care. Each of

these models show increased adolescent responsibility for healthcare management and decreased parental involvement prior to transfer. The models proposed for empirical testing differ in the focus, timing, and amount of transition programming provided. Only the Developmental Transitional Model hypothesizes a trajectory in which teens with chronic illnesses are actively assisted. In this model, adolescents are trained in healthcare management skills so that they may assume increased responsibilities and their parents or caregivers are encouraged to decrease their involvement accordingly. These increases in teen responsibility and decreases in parental involvement happen on an individualized basis during an extended period of clinical transition-focused care. Thus, increased adolescent responsibility develops as a process, in both a clinical and familial context, as the teen matures. The current investigation seeks to construct and analyze a measure of transition readiness for adolescents and young adults with kidney transplants based on the tenants of the Developmental Transitional model.

In some of the few empirical studies that have been conducted in this area, adolescent healthcare responsibility increased with age in both transplant and other pediatric populations (Annunziato et al., 2009; Fredericks et al., 2010; Pai et al., 2010; Palmer et al., 2004; Sawicki, Lukens-Bull, Yin, Demars, & Huang, 2009). Also, low levels of adolescent healthcare responsibility have been found to be a barrier to transfer (Freyer & Kibrick-Lazear, 2006). The importance of the transition process is indicated in a survey of over 18,000 adolescents with healthcare needs. Over 75% of the adolescents reported that their pediatric healthcare provider “usually encouraged” them to take responsibility for their own healthcare (Lotstein et al., 2009). However, negotiating the appropriate amount of healthcare responsibility to give adolescent transplant recipients is challenging because, although adolescence is a time of growing independence and autonomy, it is also a time of increased risk for non-adherence, allograft dysfunction, and rejection (Horslen, Barr, Christensen, Ettenger, & Magee, 2007; Magee et al., 2008). Adolescent kidney transplant recipients have the highest rates of acute rejection and rejection-related graft loss of any age group (Bell et al., 2008). These adverse outcomes are believed to be related to high rates of medication nonadherence (Dobbels et al., 2010; Simons et al., 2008). Reported rates of medication nonadherence in adolescent solid organ transplant recipients vary widely due to the use of different assessment methods with reported rates ranging from 9% to 75% (Rodrigue & Zelikovsky, 2009). A meta-analysis of studies that used a variety of adherence measurement techniques found an

average of 32% of adolescent kidney transplant recipients were nonadherent (Dobbels et al., 2010). In order to successfully transfer to adult care, teens must be adherent with medication regimens and able to assume responsibility for managing other aspects of their healthcare (e.g., call in refills, communicate with healthcare team).

In addition to encouraging responsible healthcare behavior by adolescents, parents and caregivers can give valuable support to safeguard against nonadherence throughout the transition process. Parental involvement in supervision or management of their adolescent’s healthcare tasks can be a protective factor against nonadherence (Dobbels et al., 2010; Fredericks et al., 2010; Pai et al., 2010; Simons & Blount, 2007; Zelikovsky, Schast, Palmer, & Meyers, 2008). Further, although parental involvement is frequently lessened for older adolescents (Fredericks et al., 2010; Graue, Wentzel-Larsen, Hanestad, & Søvik, 2005; Naar-King et al., 2009; Palmer et al., 2004), age should not be seen as equivalent to adolescents’ greater self-management ability or reliable performance of healthcare behaviors. Taken together, these data suggest that there is a dynamic, individualized balance between adolescent healthcare responsibility and parental involvement during the transition process, with the goal of teens taking increasing amounts of responsibility and parents becoming less involved over time, without compromising adherence.

A small number of studies assessing transition readiness or adolescents’ healthcare responsibility have been conducted in other pediatric populations (Sawicki et al., 2009), including patients with cystic fibrosis (Patton, Graham, Varlotta, & Holsclaw, 2003) and HIV (Wiener, Battles, Ryder, & Zobel, 2007). However, none of these measures of transfer readiness assess parental involvement or adolescent autonomy in healthcare management, nor do they evaluate the amount of responsibility that parents and adolescents assume in carrying out these behaviors. Conversely, there are established and promising adolescent and parent report measures of allocation of treatment responsibility and medical self-management in the areas of diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990), HIV (Naar-King et al., 2009) and transplant (Fredericks et al., 2010; Pai et al., 2010), yet these measures do not assess adolescent and parent perceptions of transition or transfer readiness.

In preparation for the development of the Readiness for Transition Questionnaire (RTQ), an extensive review of the transition literature, adolescent medicine policy statements and position papers, and existing transition measures was conducted. Given that the literature has

conceptualized transition as a process as well as an event, Overall Transition Readiness on the RTQ was operationally quantified by assessing the adolescent's readiness to assume complete responsibility for their healthcare (e.g., process) and their readiness to transfer to adult medical care (e.g., event). The components of the RTQ (e.g., Adolescent Responsibility and parental involvement) were developed based on important constructs that had been discussed, but not measured, in association with transition readiness (Annunziato et al., 2007; McDonagh, 2005; Rodrigue & Zelikovsky, 2009; While et al., 2004). The specific items on the Adolescent Responsibility and parental involvement components were selected based on the healthcare behaviors described as essential for transfer readiness by the Transition Consensus Conference of seven major transplant organizations, including the American Society of Transplantation and the United Network for Organ Sharing (Bell et al., 2008). The RTQ was written at a fifth-grade level to optimize readability, and the wording and content of items from the RTQ were then reviewed and approved by the multidisciplinary healthcare providers who designed an Adolescent Kidney Transplant Transition Clinic (AKTTC) at a large pediatric transplant center.

The purpose for the present study was to evaluate the RTQ, a novel measure of patients' and parents' perceived transition readiness for adolescent kidney transplant recipients. This study examined factors associated with transition readiness that have been identified in the theoretical and empirical literature, such as age, adolescent responsibility for healthcare, parental involvement, medication adherence, and barriers to adherence (Annunziato et al., 2009; Dobbels et al., 2010; Rodrigue & Zelikovsky, 2009; While et al., 2004; Zelikovsky et al., 2008). Additional factors of interest, which have been shown to be important in the literature on pediatric medication adherence were considered, including medication knowledge, appointment adherence, refill behavior, teen-parent relationship quality, and demographic factors (La Greca & Mackey, 2009). The RTQ scales are expected to display good internal consistency and inter rater reliability on teen and parent reports of each of the components (e.g., Overall Transition Readiness, Adolescent Responsibility, and parental involvement). Initial construct validity was expected to be supported by significant positive correlations between Overall Transition Readiness and Adolescent Responsibility on the RTQ, while parental involvement was expected to be negatively correlated with Adolescent Responsibility and Overall Transition Readiness. Initial criterion validity was expected to be supported by positive relationships between Overall

Transition Readiness and greater teen healthcare responsibility, adherence, medication knowledge, self-refill behavior, older age, and greater familial relationship quality. Fewer adolescent-perceived barriers to adherence and lower parental involvement were hypothesized to also be predictive of higher RTQ Overall Transition Readiness.

Method

Participants and Setting

The participants in this study consisted of 48 adolescent and young adult kidney transplant recipients between the ages of 15 and 21 years who were enrolled in an AKTTC at a large pediatric transplant center. Of the 54 patients enrolled at the AKTTC, 48 agreed to participate in this study (88.9%). Adolescents were excluded from the study if they were a minor and a legal guardian could not be reached to provide consent ($N=1$) or if they were deemed by the clinic psychologist to have significant cognitive impairments ($N=2$). An additional two patients were not present in clinic during data collection. Only one patient (1.9%) declined participation. Thirty-two (66.7%) of the 48 adolescents' parents and caregivers also participated in the study. Parents were excluded if they were non-English speaking ($N=4$). Twelve parents did not attend their teen's clinic appointment and either could not be reached by phone or did not return their packet after providing verbal consent by phone. The mean age of study participants was 18.6 years ($SD=1.64$ years) with an average time since transplant of 5.73 years ($SD=3.87$ years). Fifty-two percent of the sample was male. The ethnic makeup of the sample was 58.3% Caucasian, 29.2% African-American, 10.4% Hispanic, and 2.1% Asian. Twenty-eight mothers (87.5%) and four fathers completed the demographic and parent report measures.

The AKTTC was designed to facilitate the transfer of adolescent patients to adult care and to improve graft survival outcomes during the transition of healthcare responsibility process. AKTTC programming was intended to encourage patient autonomy and responsibility and improve adherence to medication and healthcare regimens by providing extensive, individually tailored behavioral and educational support to patients. Within the AKTTC, the patients have individual interactions with members of a multidisciplinary healthcare team, including a transplant coordinator, social worker, psychologist, clinical pharmacist, and pediatric nephrologist. At each clinic visit, the multidisciplinary healthcare team assesses and encourages medication adherence and knowledge, healthcare responsibility, psychosocial adjustment, and avoidance of risk behaviors.

Procedures

During their transition clinic visit, participants were recruited by research team members and presented with the appropriate informed consent, assent, and HIPAA documents prior to their participation in the study. Participants completed separate self-report measures assessing adolescent transition readiness, adherence, and barriers to adherence. Parents who attended their teen's clinic visit completed a demographics measure and a parent-report measure of adolescent transition readiness. Parents who did not attend their teen's clinic visit were contacted by phone and then mailed consent and self-report forms to return via self-addressed stamped envelope. Per clinic protocol, patients were asked semi-structured interview questions during their encounter with each member of the multidisciplinary team. Data from these encounter interviews assessing medication knowledge and relationship quality with parents were collected from the patients' electronic medical charts. In addition, relevant medical data were also collected from the patients' electronic medical records to assess adherence with clinic appointments and reported responsibility for calling in refills. Medication adherence was assessed through structured interview with the researcher at the end of the clinic visit. There was a \$10 honorarium in the form of a gift card for adolescent participants and parking vouchers for parent participants. This study was approved by the governing Institutional Review Boards.

Instruments

Demographic Questionnaire and Medical Record Review

Parents completed a demographic questionnaire that included the adolescent age, ethnicity, and education, as well as the reporting caregiver's age, ethnicity, education, income, marital status, and relationship to the child. Medical chart review was used to assess the teens' clinic appointment adherence, and medication refill behavior, as well as teen-parent relationship quality. The AKTTC protocol calls for all teens to attend quarterly multidisciplinary clinic visits, thus clinic appointment adherence was calculated as a percentage by dividing the number of clinic visits the teen attended in the past year by five (number of possible appointments including their present visit) and multiplying by 100. Medication refill behavior was coded as a dichotomous variable and assessed by looking at whether the teen reported calling in their own medication refills per the results of their interview with the AKTTC pharmacist. Finally, during their standard clinic encounter with the pediatric psychologist, teens were asked to rate

the quality of their relationship with their parents on a 5-point Likert-type scale which includes: "1-poor," "2-fair," "3-good," "4-very good," and "5-excellent." The teen-parent relationship quality data from this interaction with the psychologist was recovered from the teens' medical record.

Readiness for Transition Questionnaire (RTQ-teen; RTQ-parent)

The RTQ was created for use in this study to assess Overall Transition Readiness; Adolescent Responsibility (AR), or the frequency of responsible adolescent healthcare behavior; and parental involvement, the frequency of familial involvement in their teen's healthcare. Adolescents and their caregivers completed parallel versions of the RTQ. Items from the RTQ-teen are listed in Table I. Adolescents' Overall Transition Readiness (Teen RTQ-Overall, Parent RTQ-Overall) scores could range from 2 to 8. The RTQ-Overall score was obtained by summing scores for the following items: "Overall, how ready do you think you are (or your teen is) to assume complete responsibility for your healthcare?" and "Overall, how ready do you think you are (or your teen is) to transition from care at (specific name for this pediatric hospital) to adult care? 1-not at all ready, 2-somewhat ready, 3-mostly ready, 4-completely ready." Thus, higher Overall Transition Readiness scores indicate greater perceived readiness for healthcare responsibility as well as greater perceived readiness to transfer to adult care.

In addition to reporting on overall transition readiness, parents and teens also reported on the current frequency of adolescent responsibility and parental involvement for 10 specific healthcare behaviors (e.g., scheduling specialty care appointments, scheduling primary care appointments, attending medical appointments, calling in refills, taking medication daily, communicating with medical staff in person, communicating with medical staff via phone, explaining their medical condition to others, getting monthly labs, and knowing terms of insurance) identified in the literature as being key for successful transition to adult care (Bell et al., 2008; Wiener et al., 2007). Frequency of Adolescent Responsibility (Teen RTQ-AR, Parent RTQ-AR) for each of the 10 healthcare behaviors was rated on a four point Likert-type scale with verbal anchors of "1-not at all responsible" and "4-responsible almost all the time." Parents and teens also rated the frequency of parental involvement in each of the 10 healthcare behaviors (Teen RTQ-PI, Parent RTQ-PI) on a four point Likert-type scale with verbal anchors of "1-not at all involved" and "4-involved almost all the time." Hence, the RTQ components of responsible adolescent healthcare

Table 1. *Readiness for Transition Questionnaire-Teen (RTQ-teen)*

Please rate YOUR RESPONSIBILITY for the following healthcare behaviors...	1-Not responsible at all 2-Sometimes responsible 3-Often responsible 4-Almost always responsible			
	1	2	3	4
Getting monthly labs	1	2	3	4
Taking medication daily as prescribed	1	2	3	4
Scheduling specialty care appointments (e.g., transition clinic)	1	2	3	4
Scheduling primary care appointments	1	2	3	4
Calling in or ordering refills	1	2	3	4
Explaining your medical condition to others	1	2	3	4
Knowing details about your insurance coverage (e.g., plan, copays, eligibility)	1	2	3	4
Attending medical appointments	1	2	3	4
Communicating with medical staff in person	1	2	3	4
Communicating with medical staff over the phone	1	2	3	4

Please rate PARENT INVOLVEMENT for the following healthcare behaviors...	1-Not involved at all 2-Sometimes involved 3-Often involved 4-Almost always involved			
	1	2	3	4
Getting monthly labs	1	2	3	4
Taking medication daily as prescribed	1	2	3	4
Scheduling specialty care appointments (e.g., transition clinic)	1	2	3	4
Scheduling primary care appointments	1	2	3	4
Calling in or ordering refills	1	2	3	4
Explaining your medical condition to others	1	2	3	4
Knowing details about your insurance coverage (e.g., plan, copays, eligibility)	1	2	3	4
Attending medical appointments	1	2	3	4
Communicating with medical staff in person	1	2	3	4
Communicating with medical staff over the phone	1	2	3	4

Overall, how ready do you think you are...	1-Not at all ready 2-Somewhat ready 3-Mostly ready 4-Completely ready			
	1	2	3	4
Assume complete responsibility for your healthcare?	1	2	3	4
Transfer from care at a children's hospital to adult care?	1	2	3	4

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behavior (RTQ-AR) and frequency of parental involvement in their teen's healthcare (RTQ-PI) each range from 10 to 40 with higher scores denoting increased adolescent responsibility or caregiver involvement.

Adolescent Medication Barriers Scale

The adolescent medication barriers scale (AMBS) was designed to measure perceived barriers to medication taking and was developed using an adolescent solid organ transplant sample (Simons & Blount, 2007). Items were rated on a 5-point Likert-type scale ranging from "1-strongly disagree" to "5-strongly agree." The 17 items on the AMBS showed strong internal consistency in the current sample (Cronbach's $\alpha = .907$).

Adolescent Report of Medication Adherence and Medication Knowledge

The Medical Adherence Measure, the Medication Adherence Module (MAM) is a semi-structured interview used to assess adolescent self-report of medication adherence (Zelikovsky & Schast, 2008). In this study, the pharmacist administered the Medication Knowledge portion of the MAM as part of the standard clinic encounter, and researchers administered the Medication Adherence portion of the MAM for study purposes at the end of the clinic visit. Adolescents reported on how many doses of medication were missed or taken late over the past week. Percentages of missed and late doses were calculated by dividing the number of missed or late doses by the total number of doses prescribed for the week multiplied by

100. Similar to a previous investigation, adherence in this sample was examined as a dichotomous variable with teens who reported missing any doses or taking more than 10% of doses late coded as nonadherent and teens who reported missing no doses and taking less than 10% of doses late coded as adherent (Simons et al., 2008). Medication knowledge was evaluated by asking the adolescents to recall the medication name, dosage, frequency, and indication. Responses were compared with the medical chart with a possible total score of 4 for each correct answer for each medication. An overall medication knowledge score was obtained by adding the score from each of the medications, dividing by four times the number of medications prescribed, and multiplying by 100. For data analysis, medication knowledge was examined as a dichotomous variable with teens exhibiting complete medication knowledge (e.g., 100%) versus less than complete medication knowledge.

Results

Overview of Analyses

Preliminary correlational and between-group analyses assessed the association between demographic factors and measures from the RTQ (Adolescent Responsibility, parental involvement, and Overall Transition Readiness). Next, to establish initial reliability for the RTQ, correlations between teen and parent report on the RTQ components were calculated along with subscale internal consistencies. The overall construct validity of the measure was assessed by evaluating hierarchical linear regression models of Overall Transition Readiness using age, Adolescent Responsibility, and parental involvement as independent predictors (While et al., 2004). Pearson correlational analyses were conducted to investigate the criterion validity of the RTQ by determining associations between psychosocial and adherence variables and adolescent and parent report of Adolescent Responsibility, parental involvement, and Overall Transition Readiness. From the correlation matrix, psychosocial and adherence variables were considered for entry into hierarchical linear regression models predicting adolescent and parent reports of Overall Transition Readiness.

Preliminary Analyses

Preliminary analyses were conducted to examine relationships between demographic factors, parental participation, and outcome variables. For the adolescent sample as a whole ($N = 48$), there were no significant differences in gender, ethnicity, or time since transplant on Adolescent Responsibility, parental involvement, or Overall Transition

Readiness from the RTQ. The gender and ethnicity analyses were rerun on the subset of the 32 adolescents whose parents participated in the study, and no significant differences were found for gender or ethnicity for these RTQ variables. Age was not included in these preliminary analyses as it is used as a predictor in all validity analyses. Additional preliminary analyses were conducted to evaluate differences in demographic factors and the RTQ scales for adolescents whose parents participated ($N = 32$) versus those whose parents did not participate ($N = 16$). Results indicated that adolescents whose parents participated in the study were more likely to be younger adolescents (Participating: $M = 18.25$ years, $SD = 1.71$ years, nonparticipating: $M = 19.38$ years, $SD = 1.16$ years, $t = -3.09$, $p = .004$) and Caucasian ($t = 3.24$, $p = .003$). Analyses showed no significant differences on the Teen RTQ between teens whose parents participated versus teens whose parents did not.

Reliability Analyses

The relationships among the Teen RTQ and Parent RTQ variables were examined using Pearson product-moment correlation coefficients. Teen and parent reports of overall transition readiness (RTQ-Overall $r = .68$, $p \leq .01$), adolescent responsibility (RTQ-AR $r = .50$, $p \leq .01$), and parental involvement (RTQ-PI $r = .58$, $p \leq .01$) were significantly correlated across informants. In addition, all of the components of the RTQ demonstrated strong internal consistencies, including the two item Overall Transition Readiness component (Teen RTQ-Overall Cronbach's $\alpha = .79$; Parent RTQ-Overall Cronbach's $\alpha = .88$), the 10 item Adolescent Responsibility component (Teen RTQ-AR Cronbach's $\alpha = .86$; Parent RTQ-AR Cronbach's $\alpha = .85$) and the 10 item parental involvement component (Teen RTQ-PI Cronbach's $\alpha = .94$; Parent RTQ-PI Cronbach's $\alpha = .89$).

Validity Analyses

In order to provide initial validity data for the RTQ, Pearson correlational analyses were conducted to investigate the associations between psychosocial and adherence variables and adolescent and parent report of Adolescent Responsibility, parental involvement, and Overall Transition Readiness. Table II displays the bivariate relationships between the adolescent and parent report on the RTQ scales and age with specific indicators of transition readiness. Age was correlated with decreased teen and parent reports of parental involvement with older patients having less parental involvement. Age was not correlated with teen or parent report of Overall

Table II. RTQ Correlates of Teen and Parent Report of Transition Readiness

Variable	1 Teen age	2 Teen RTQ- overall	3 Parent RTQ- overall
1. Teen age (<i>N</i> = 48, <i>M</i> = 18.60, <i>SD</i> = 1.635)	–	.25	.13
2. Overall transition readiness-Teen report (teen RTQ-Overall) (<i>N</i> = 48, <i>M</i> = 5.96, <i>SD</i> = 1.487)	.25	–	.68**
3. Overall transition readiness-Parent report (parent RTQ-Overall) (<i>N</i> = 32, <i>M</i> = 4.41, <i>SD</i> = 1.864)	.13	.68**	–
4. Adolescent responsibility-Teen report (teen RTQ-AR) (<i>N</i> = 48, <i>M</i> = 32.96, <i>SD</i> = 5.731)	.20	.68**	.65**
5. Adolescent responsibility-Parent report (parent RTQ-AR) (<i>N</i> = 32, <i>M</i> = 25.56, <i>SD</i> = 6.877)	.19	.62**	.71**
6. Parental involvement-Teen report (teen RTQ-PI) (<i>N</i> = 48, <i>M</i> = 29.15, <i>SD</i> = 8.956)	–.53**	–.39**	–.49**
7. Parental involvement-Parent report (parent RTQ-PI) (<i>N</i> = 32, <i>M</i> = 32.38, <i>SD</i> = 7.088)	–.51**	–.39*	–.41*
8. Medication adherence (MAM) (<i>M</i> = 0.38, <i>SD</i> = 0.489) Dichotomous classification (<i>M</i> = 3.51%, <i>SD</i> = 13.27%) Doses missed	.14	–.15	–.08
9. Medication knowledge (MAM) (<i>M</i> = 0.44, <i>SD</i> = 0.501) Dichotomous classification (<i>M</i> = 88.57%, <i>SD</i> = 16.41%) Percent correct	.09	.40*	.44*
10. Overall medication barriers (AMBS) (<i>M</i> = 32.08, <i>SD</i> = 12.687)	.08	–.36*	–.33
11. Appointment adherence (<i>M</i> = 86.67, <i>SD</i> = 15.065)	–.07	.20	.05
12. Calls in refills (<i>M</i> = 1.77, <i>SD</i> = 0.425)	.50**	.36*	.48**
13. Teen–parent relationship quality (<i>M</i> = 3.62, <i>SD</i> = 1.123)	–.09	.30*	.08

Note. * $p \leq .05$, ** $p \leq .01$.

Transition Readiness or Adolescent Responsibility. Teen and parent reports of Overall Transition Readiness were positively correlated with teen and parent reports of Adolescent Responsibility and negatively correlated with reports of parental involvement, such that patients who were deemed more transition ready also reportedly had more responsibility in their healthcare and less parental involvement. Additionally, parent report of Adolescent Responsibility was negatively correlated with teen report of parental involvement, showing that teens who were deemed to have more responsibility also reported less parental involvement.

Further correlational analyses were conducted to assess the degree to which scores on the RTQ were associated with healthcare and family variables (Table II). There were significant positive relationships between teen report of Overall Transition Readiness and adolescent medication knowledge, adolescent report of calling in refills, and teen–parent relationship quality; additionally,

there was a significant negative relationship between teen report of Overall Transition Readiness and adolescent report of medication barriers. There were significant positive relationships between parent report of Overall Transition Readiness and adolescent medication knowledge and adolescent report of calling in refills. Adolescent medication adherence was not significantly related to teen or parent report of Overall Transition Readiness.

To support the construct validity of the RTQ, two separate regression analyses were used to predict teen and parent report of Overall Transition Readiness. Hierarchical regression analyses were conducted so that the individual contributions of each related construct could be evaluated. Adolescent age was entered as Block 1 into the Overall Transition Readiness models. Adolescent Responsibility was entered on the second block with parental involvement on the third block. Both the adolescent [$R^2 = .53$, $F(3, 44) = 16.60$, $p < .001$,

Table III. Hierarchical Regression of Transition Readiness: Adolescent Responsibility and Parental Involvement

	B ^a	SEB ^b	β ^c	R ²	ΔR ²	F
Teen report of overall transition readiness (Teen RTQ; N = 48)						
Step 1: Adolescent age (M = 18.60, SD = 1.635)	.22	.13	.25 [†]	.06	.06 [†]	2.98 [†]
Step 2: Adolescent age	.10	.10	.11			
Adolescent responsibility (RTQ-teen AR)	.17	.03	.66**	.48	.42**	20.78**
Step 3: Adolescent age	-.02	.11	-.03			
Adolescent responsibility (RTQ-teen AR)	.16	.03	.63**			
Parental involvement (RTQ- teen PI)	-.05	.02	-.27*	.53	.05*	16.60**
Parent report of overall transition readiness (Parent RTQ; N = 32)						
Step 1: Adolescent age (M = 18.17, SD = 1.682)	.15	.20	.13	.02	.02	.54
Step 2: Adolescent age	.00	.15	.00			
Adolescent responsibility (RTQ-parent AR)	.19	.04	.71**	.50	.48**	14.65**
Step 3: Adolescent age	-.14	.16	-.12			
Adolescent responsibility (RTQ-parent AR)	.07	.03	.65**			
Parental involvement (RTQ- parent PI)	-.07	.04	-.27 [†]	.55	.05 [†]	11.49**

Note. ^aB, unstandardized coefficients.

^bSEB, standard error of unstandardized coefficients.

^cβ, standardized coefficients.

* $p \leq .05$, ** $p \leq .01$, [†] $p \leq .10$.

Cohen's $f^2 = 1.13$] and parent models [$R^2 = .55$, $F(3, 28) = 11.49$, $p < .001$, Cohen's $f^2 = 1.22$] predicted a large portion of the variance in Overall Transition Readiness scores. Table III displays that age alone accounted for a nonsignificant 6% and 2% of the variance in teen and parent models, respectively. Adolescent responsibility accounted for a significant 42% and 48% increment to the variance accounted for in the teen and parent models, respectively. Decreased parental involvement accounted for an additional significant 5% of the variance in the teen model and a nonsignificant additional 5% in the parent model. Adolescent age, increased Adolescent Responsibility, and decreased parental involvement together accounted for 53% and 55% of the variance in the teen and parent models of Overall Transition Readiness, respectively.

To evaluate our hypotheses about adherence, health behavior, and familial relationship quality, two separate regression models were created to evaluate predictors of teen and parent report of Overall Transition Readiness on the RTQ. Again, hierarchical regression analyses were conducted so that the individual contributions of each related construct could be evaluated. In these models, adolescent age was entered on the first step. On the second step, all adherence-related variables that were statistically significant at the bivariate level were entered. In addition to these statistically significant variables, appointment adherence was also entered on the second step in the adolescent model for exploratory purposes, as appointment adherence is particularly important during transfer

to adult healthcare providers. For the parent model, adolescent report of medication barriers was also entered on the second step to parallel the adolescent model and because the correlation value between medication barriers and Overall Transition Readiness was similar across adolescent and parent report. Finally, for the adolescent model, teen–parent relationship quality, which was significantly correlated with Overall Transition Readiness, was entered on the third step. The adolescent model [$R^2 = .44$, $F(6, 41) = 5.50$, $p < .001$, Cohen's $f^2 = .786$] and parent model [$R^2 = .43$, $F(4, 27) = 5.12$, $p = .003$, Cohen's $f^2 = .754$] each predicted large portions of the variance in Overall Transition Readiness scores. Table IV displays that age accounted for a nonsignificant 6% of the variance in teen report of Overall Transition Readiness, with adherence factors and teen–parent relationship quality adding significant 33% and 5% increments, respectively. Age, clinic appointment attendance, adherence behavior, and teen–parent relationship quality together accounted for 44% of the variance in teen report of Overall Transition Readiness. Significant predictors in the final adolescent model included decreased adolescent barriers to medication adherence, complete knowledge of their medication regimen, and better teen–parent relationship quality. For the parent report model of Overall Transition Readiness, Table IV displays that age accounted for a nonsignificant 2% of the variance in parent report of Overall Transition Readiness, with adherence factors adding a significant 41% increment. Age and adherence factors together accounted for 43% of the variance in parent

Table IV. Hierarchical Regression of Transition Readiness, Adherence Behaviors, and Teen-Parent Relationship

	B ^a	SEB ^b	β ^c	R ²	Δ R ²	F
Teen report of overall transition readiness (Teen RTQ; N = 48)						
Step 1: Adolescent age (M = 18.60, SD = 1.635)	.22	.13	.25 [†]	.06	.06 [†]	2.98 [†]
Step 2: Adolescent age	.14	.13	.15			
Barriers to medication adherence (AMBS-total)	-.04	.02	-.35**			
Medication knowledge (MAM-knowledge)	.79	.37	.27*			
Calls in medication refills	.77	.5	.22			
Clinic appointment adherence	.02	.01	.22 [†]	.39	.33**	5.42**
Step 3: Adolescent age	.15	.13	.10			
Barriers to medication adherence (AMBS-total)	-.03	.12	-.28*			
Medication knowledge (MAM-knowledge)	.74	.36	.25*			
Calls in medication refills	.85	.48	.24 [†]			
Clinic appointment adherence	.02	.01	.24 [†]			
Teen-parent relationship quality	.33	.16	.25*	.44	.05*	5.50**
Parent report of overall transition readiness (Parent RTQ; N = 32)						
Step 1: Adolescent age (M = 18.17, SD = 1.682)	.15	.2	.13	.02	.02	.54
Step 2: Adolescent age	-.15	.19	-.13			
Barriers to medication adherence (AMBS- total)	-.03	.02	-.20			
Medication knowledge (MAM- knowledge)	1.3	.56	.35*			
Calls in medication refills	1.87	.68	.47**	.43	.41**	5.12**

Note. ^aB, unstandardized coefficients.

^bSEB, standard error of unstandardized coefficients.

^cβ, standardized coefficients.

* $p \leq .05$, ** $p \leq .01$, [†] $p \leq .10$.

report of Overall Transition Readiness. Significant predictors in the final parent model included teens showing complete knowledge of their medication regimen and teens calling in their medication refills.

Discussion

The current study addresses a gap in the pediatric healthcare transition literature. Although a few measures of transition readiness exist in the literature (Patton et al., 2003; Sawicki et al., 2009; Wiener et al., 2007), none of these instruments were specifically developed for use with transplant recipients, assess both teen and parent report, and assess parental involvement in teens' healthcare activities. Thus, the RTQ provides a more complete picture by including multiple reporters and by detailing perceptions about overall transition readiness and adolescent and parent healthcare behavior. The preliminary psychometrics of the RTQ appear to be robust. The 10 items on each of the Adolescent Responsibility and parental involvement components of the RTQ showed strong internal consistency with Cronbach's α 's ranging in the mid-.80s to low-.90s. Correlations across informants among the teen and parent completed scales were significantly large and in the expected direction. Also,

the construct validity of the components of the RTQ was further supported by the significant relationships with the other variables assessed in this investigation. The RTQ has the potential to be utilized by healthcare providers to quickly screen both patients' and parents' perceptions about transition readiness and identify potential deficits in healthcare responsibility and self-management prior to transfer to adult care. On the whole, the RTQ appears to be an easily administered, readable, and psychometrically supported measure which could be used clinically to assess transition readiness from parent and teen perspectives.

Similar to what has been hypothesized in position papers in the literature, our adolescent model of Overall Transition Readiness shows strong relationships with increased Adolescent Responsibility and decreased parental involvement (While et al., 2004). High adolescent responsibility and correspondingly lower parental involvement represent the goal of both preparing the adolescents to transfer to adult healthcare and for the successful management of key aspects of their healthcare needs with less reliance on their parents. The parent model also demonstrates a strong relationship between increased Adolescent Responsibility and Overall Transition readiness. Although the parent model did not show decreased parental involvement as a significant predictor of overall

transition readiness, it did account for 5% of the variance in both models. Thus, lack of significance may have been due to lower statistical power in the parent versus the adolescent model. Interestingly, adolescent age was not a significant predictor in either the teen or the parent model of transition readiness. These findings are particularly important in that increasing age was associated with both adolescent and parent reports of less parental involvement. Therefore, as the safety net of parental involvement decreases, assuring adolescents are equipped to assume responsibility for their own healthcare is critical. These findings are congruent with the transition literature which emphasizes the importance of adolescents' reliable performance of healthcare behaviors over chronological age as being indicative of transition and transfer readiness (Bell et al., 2008; Rodrigue & Zelikovsky, 2009).

This investigation identified several behavioral indices associated with perceived transition readiness. Transition readiness was associated with adolescent adherence factors including fewer barriers to medication adherence, complete knowledge of their medication regimen, and independence with calling in refills. Thus, transition readiness is not only associated with knowing their medication regimen, but also having fewer factors that interfere with that regimen and independently acting when refills are needed to continue that regimen. Surprisingly, there were no significant associations between transition readiness and adolescent self-report of medication adherence on the MAM. Perhaps this nonsignificant finding has to do with patients underreporting nonadherence to please healthcare providers or the short-term nature of the self-report of adherence as assessed by the MAM (e.g., past 7 days) versus the long term and cumulative process of becoming ready to transition. Finally, better teen–parent relationship quality was also associated with adolescent report of increased transition readiness and fewer barriers to medication adherence. Research has documented the importance of the high-quality parent–child relationships on adolescents' autonomy development (Steinberg, 2001). A high-quality family relationship may be facilitative of learning, growth, and independence in adolescents, while simultaneously being associated with fewer factors such as high adolescent rebellion, emotional distress, and chaotic conditions that would interfere with becoming ready to transition. Further, relationship quality may influence adolescents' reactions to parental efforts to encourage their assumption of greater responsibility for their healthcare, as well as their receptiveness to direct parental interventions such as prompting to ensure medication adherence.

There are several limitations to this project which are important to describe here and address in future studies.

Despite efforts to collect data from all parents of teen participants, data were not available from all caregivers. Therefore, the results of the parent models may not be reflective of the AKTTC as a whole, given adolescent age and ethnic differences found between parental responders versus nonresponders. Future studies should make intensive efforts to collect data from all parents and caregivers. Additionally, our information about family-relationship quality was based on Likert ratings by the teens during interviews with the clinic psychologist. Given that this one exploratory item was significant in the teen model, future studies should employ an evidence-based family functioning measure to assess both parent and teen opinions of relationship quality. Although this investigation collected data from over 85% of patients in the AKTTC affiliated with a large pediatric transplant center, only 48 adolescents participated. Future research should utilize multisite recruitment in order to yield a larger sample size. A larger sample of adolescent transplant recipients would allow for more complete testing of the predictors in the regression models and detection of smaller significant effects, as well as determine if these findings generalize to other pediatric kidney transplant recipients. Also, the literature conceptualizes transition as both a process and an event as patients move from pediatric to adult care. This investigation developed a measure with promising initial psychometrics, but longitudinal data to assess both sensitivity to change over time and participants' responsibility posttransfer were not collected. These should be included in future validation studies. Our ability to evaluate those end points awaits a sufficient number of patients graduating from this relatively new transition clinic. Future investigations utilizing the RTQ should evaluate its predictive validity by including follow-up of posttransfer medical and psychosocial outcomes. Lastly, the measure of transition readiness created for this study was developed in an adolescent and young adult sample of kidney transplant recipients receiving active, transition-focused clinical programming. Additional research is needed to explore the potential clinical utility of using the RTQ to screen for transition readiness in other organ transplant recipients and pediatric populations, regardless of whether they are participating in formal transition readiness training.

In conclusion, this investigation addresses the importance of preparing adolescents and their families for transfer to adult care. Factors associated with readiness were identified. Though the empirical transition of healthcare responsibility literature may be sparse, it is clear that the medical and emotional costs of being

unprepared for transfer to adult services can be devastatingly high, with possible consequences including allograft loss and death (Annunziato et al., 2007; Watson, 2000). Additional research should evaluate transitional programming to identify which training components are related to improvements in transition readiness, adolescent responsibility, and medical outcomes. The RTQ could be utilized in studies of this kind and may help identify critical components that could refine transition readiness programming. Finally, future investigations should target parents of teens in transition and identify ways to assist parents in decreasing their involvement while simultaneously encouraging adolescent adherence and health-care responsibility. With an increased knowledge of effective, family-centered transition programming, we can more confidently assist adolescent patients as they are getting ready to leave pediatrics for the world of adult care.

Funding

This research project was funded by grants from the University of Georgia and the Marguerite and Carlos Mason Trust at Children's Healthcare of Atlanta.

Conflicts of interest: None declared.

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THE UNIVERSITY
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STARx Questionnaire - Parents

SMOOTH TRANSITION TO ADULTHOOD WITH RX=TREATMENT

Created by Maria Díaz-González de Ferris, MD, MPH, PhD with assistance from Sue Tolleson-Rinehart, PhD; Ms. Kristi Bickford; Carol Ford, MD; Caroline Jennette, MSW; Susan Hogan, PhD; Donna Harward, Med; Nicole Fenton, PhD; Bradley Layton, PhD; Lynn McCoy, RN; Mr. James O'Neill, Mr. Robert Imperial, the UNC adolescent patients and Teresa Edwards Version 18_03_21

Section 1 Directions: Please check the one that shows how often your child has done each thing **in the past 3 months**.

	Never	Almost Never	Sometimes	Almost Always	Always	Not needed for my child's care
1. How often did your child make an effort to understand what his/her doctor told them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How often did your child take his/her medicines on their own?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How often did your child ask his/her doctor or nurse questions about their illness, medicines or medical care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How often did your child make their own appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How often did your child need someone to remind him/her to take their medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How often did your child use things likes pillboxes, schedules, or alarm clocks to help him/her take their medicines when they were supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How often did your child use the internet, books or other guides to find out more about his/her illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How often did your child forget to take his/her medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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9. How often did your child work with his/her doctor to take care of new health problems that came up?

Section 2 Directions:

- **Some patients know a lot about their health and some patients do not.**
- **How much does your child know? Please check the answer that describes your child most.**

	Nothing	Not Much	A Little	Some	A Lot	Not needed for my child's care
10. How much does your child know about his/her illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. How much does your child know about taking care of his/her illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. How much does your child know about what will happen if he/she does not take their medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 3 Directions: **Some patients may find it hard to do certain things. Please check what best describes how easy or hard you feel this is/will be for your child.**

	Very Hard	Somewhat Hard	Neither hard nor easy	Somewhat Easy	Very Easy	Not needed for my child's care
13. How easy or hard is it for your child to talk to his/her doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. How easy or hard is it for your child to make a plan with his/her doctor to care for his/her health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. How easy or hard is it for your child to see his/her doctor by himself or herself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. How easy or hard is it for your child to take his/her medicines like they are supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. How easy or hard is it for your child to take care of himself/herself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. How easy or hard do you think it will be for your child to move from pediatrics to adult-focused care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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STARx Questionnaire for Patients in Adult-focused Settings

SELF-MANAGEMENT IN ADULTHOOD WITH RX=TREATMENT

Created by Maria Díaz-González de Ferris, MD, MPH, PhD with assistance from Sue Tolleson-Rinehart, PhD; Ms. Kristi Bickford; Carol Ford, MD; Caroline Jennette, MSW; Susan Hogan, PhD; Donna Harward, Med; Nicole Fenton, PhD; Bradley Layton, PhD; Lynn McCoy, RN; Mr. James O'Neill, Mr. Robert Imperial, the UNC adolescent patients and Teresa Edwards Version 18_03_21

Section 1 Directions: Please check the one that shows how often you have done each thing **in the past 3 months**.

	Never	Almost Never	Sometimes	Almost Always	Always	Not needed for my child's care
1. How often did you make an effort to understand what your doctor told you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How often did you take your medicines on your own?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How often did you ask doctors or nurses questions about your illness, medicines or medical care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How often did you make your own appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How often did you need someone to remind you to take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How often did you use things like pillboxes, schedules, or alarm to help you take their medicines when they were supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How often did you use the internet, books or other guides to find out more about his/her illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How often did your forget to take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. How often did you work with your doctor to take care of new health problems that came up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Created by Maria Díaz-González de Ferris, MD, MPH, PhD with assistance from Sue Tolleson-Rinehart, PhD; Ms. Kristi Bickford; Carol Ford, MD; Caroline Jennette, MSW; Susan Hogan, PhD; Donna Harward, Med; Nicole Fenton, PhD; Bradley Layton, PhD; Lynn McCoy, RN; Mr. James O'Neill, Mr. Robert Imperial, the UNC adolescent patients and Teresa Edwards *Version 18_03_21*

Section 2 Directions:

- **Some patients know a lot about their health and some patients do not.**
- **How much does you know? Please check the best answer.**

	Nothing	Not Much	A Little	Some	A Lot	Not needed for my care
10. How much do you know about your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. How much does you know about taking care of your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. How much does you know about what will happen if you do not take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 3 Directions: **Some patients may find it hard to do certain things. Please check what best describes how easy or hard you feel it will be for you.**

	Very Hard	Somewhat Hard	Neither hard nor easy	Somewhat Easy	Very Easy	Not needed for my care
13. How easy or hard is it for you to talk to your doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. How easy or hard is it for you to make a plan with your doctor to care for your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. How easy or hard is it for you to see your doctor by yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. How easy or hard is it for you to take your medicines the way they are supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. How easy or hard is it for you to take care of yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. How easy or hard do you think it will be for you to find other doctors?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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STARx Questionnaire for Patients in the Pediatric Settings

SELF-MANAGEMENT AND TRANSITION TO ADULTHOOD WITH RX=TREATMENT

Created by Maria E. Díaz-González de Ferris, MD, MPH, PhD with assistance from Sue Tolleson-Rinehart, PhD; Ms. Kristi Bickford; Carol Ford, MD; Caroline Jennette, MSW; Susan Hogan, PhD; Donna Harward, MEd; Nicole Fenton, PhD; Bradley Layton, PhD; Lynn McCoy, RN; Mr. James O'Neill, Mr. Robert Imperial, the UNC adolescent patients and Teresa Edwards *Version 4.0_18_03_21*

Section 1 Directions: Please check the one that shows how often you have done each thing **in the past 3 months**.

	Never	Almost Never	Sometimes	Almost Always	Always	I do not take any medicine
1. How often did you make an effort to understand what your doctor told you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2. How often did you take your medicines on your own?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How often did you ask doctors or nurses questions about your illness, medicines or medical care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
4. How often did you make your own appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
5. How often did you need someone to remind you to take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How often did you use things like pillboxes, schedules, or alarm to help you take their medicines when they were supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How often did you use the internet, books or other guides to find out more about his/her illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8. How often did your forget to take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. How often did you work with your doctor to take care of new health problems that came up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Created by Maria E. Díaz-González de Ferris, MD, MPH, PhD with assistance from Sue Tolleson-Rinehart, PhD; Ms. Kristi Bickford; Carol Ford, MD; Caroline Jennette, MSW; Susan Hogan, PhD; Donna Harward, MEd; Nicole Fenton, PhD; Bradley Layton, PhD; Lynn McCoy, RN; Mr. James O'Neill, Mr. Robert Imperial, the UNC adolescent patients and Teresa Edwards Version 4.0_18_03_21

Section 2 Directions:

- **Some patients know a lot about their health and some patients do not.**
- **How much does you know? Please check the best answer.**

	Nothing	Not Much	A Little	Some	A Lot	I do not take any medicine
10. How much do you know about your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
11. How much does you know about taking care of your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
12. How much does you know about what will happen if you do not take your medicines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 3 Directions: **Some patients may find it hard to do certain things. Please check what best describes how easy or hard you feel it will be for you.**

	Very Hard	Somewhat Hard	Neither hard nor easy	Somewhat Easy	Very Easy	I do not take any medicine
13. How easy or hard is it for you to talk to your doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
14. How easy or hard is it for you to make a plan with your doctor to care for your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
15. How easy or hard is it for you to see your doctor by yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
16. How easy or hard is it for you to take your medicines the way they are supposed to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. How easy or hard is it for you to take care of yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
18. How easy or hard do you think it will be for you to move from pediatrics to adult-focused care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Patient Name		Date	
Medical Record #	Transition ID	Institution	

UNC T.R_xA.N.S.I.T.I.O.N. Scale™ for Parents:

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

Type of chronic health condition

		Correct	Non-specific	Incorrect
1	What is the name of your child's health condition?	1.0	0.5	0.0
2	What physical symptoms does your child experience because of their health condition?	1.0	0.5	0.0
3	How might [name of health condition] affect your child's health in the future?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T		_____ out of 3
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

R_x: Medications

		Can name all	Can name some	Cannot name any	N/A
[Write in prescribed meds in advance; enter the total number of meds in the middle column ("Number of Meds") for each question in this section] _____ _____ _____		1.0	0.5	0.0	
4	What are the names of the medicines, vitamins, and/or supplements your child is supposed to be taking for their health condition?	1.0	0.5	0.0	
5	When is your child supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
6	What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
7	What could happen to your child if he/she did not take [name each medication, vitamin, and supplement patient should be taking] like the doctor has asked them to?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal R _x		_____ out of _____	
<i>Divide the subtotal by the number of possible points</i>		Proportion R _x			

This instrument was created with assistance from: UNC adolescent patients, the UNC interdisciplinary Transition team, and Teresa Edwards of the UNC Odum Institute; and with funding from: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust.

This form has been approved by the IRB for use between 02/23/2012 and 02/21/2013

Adherence

		Yes	Sometimes	No	N/A
8	In a typical week, does your child usually miss a full day of medicine, either because he/she forgot to take it or didn't want to take it?	0.0	0.5	1.0	
9	Does your child usually have trouble remembering to take his/her medicines every day?	0.0	0.5	1.0	
10	Does your child usually come to their doctor appointments when they are scheduled?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal A		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion A			

Nutrition

		Yes	Has an idea	No	
11	When choosing foods and drinks, does your child read the nutrition labels on them to find out if they are healthy choices?	1.0	0.5	0.0	
12	Is your child supposed to follow any special diet because they have [name of health condition]?	1.0	0.5	0.0	
13	<i>[if the patient is on a special diet]</i> What are examples of foods and drinks your child should have more or less of?	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>		Subtotal N		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N			

Self-management skills

		Yes	Sometimes	No	N/A
14	Does your child usually remember to take his/her medicines on their own?	1.0	0.5	0.0	
15	Does someone usually have to remind your child to take their medicines?	0.0	0.5	1.0	
16	Does your child usually call in their prescription refills himself/herself?	1.0	0.5	0.0	
17	Does your child usually pick-up refills from the pharmacy himself/herself?	1.0	0.5	0.0	
18	Does your child usually call or email his/her doctor when they have a question or need to speak with him/her?	1.0	0.5	0.0	

19	Does your child usually make their own doctor appointments?	1.0	0.5	0.0	
20	<i>[if the patient has medical procedures to perform]</i> Does your child usually perform his/her medical procedures on their own (catheterization, insulin shots, etc)?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal S	___ out of ___		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion S			

Issues of reproduction

		Knows definitely	Has an idea	Does not know	
21	Will your child's health condition likely affect his/her ability to: <i>[if female]</i> become pregnant? <i>[if male]</i> get someone pregnant?	1.0	0.5	0.0	
22	<i>[Females only]</i> What risks might your child face if/when she becomes pregnant because she has [name of health condition]?	1.0	0.5	0.0	N/A
23	<i>[Females only]</i> Does your child take any medicines that would be harmful to an unborn baby if she became pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD's?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I			
<i>Male</i>		___ out of 2			
<i>Female</i>		___ out of 4			
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			

Trade / School

		Knows definitely	Has an idea	Does not know	
25	What are your child's future plans in regards to school and/or a job?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal T	___ out of 1		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T			

Insurance

		Knows definitely	Has an idea	Does not know	
26	What is health insurance and why it is important for your child to have?	1.0	0.5	0.0	
27	What is the name of your child's current health insurance provider?	1.0	0.5	0.0	
28	<i>[If child is currently insured]</i> At what age will your child's current health insurance coverage end?	1.0	0.5	0.0	N/A
29	How can your child get health insurance coverage for himself/herself when they age out of their current coverage?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I	___ out of ___		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			

Ongoing support

		S/he will do it	Parents / friends	Does not know	
30	When your child becomes an adult, who will manage his/her health condition? For example, help them remember to take their medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments.	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal 0	___ out of 1		

New health care providers

		Knows definitely	Has an idea	Does not know	
31	When it comes time for your child to switch to an adult doctor, how will you find one?	1.0	0.5	0.0	
32	In order to get your child's medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal N	___ out of 2		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N			

Raw total score	<i>Sum all section subtotals here (max 32)</i>	
T.R_xA.N.S.I.T.I.O.N Score™	<i>Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)</i>	

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

Transition Readiness Tools

Transition readiness tools provide a method of assessment of self-management and related competencies for adolescents and emerging adults.

A variety of generic and condition-specific transition readiness measures have been developed. The links below are not meant to be exhaustive, but represent options that have been studied to develop evidence for construct validity.

The Society of Pediatric Nurses does not endorse the use of any one tool over another. Before selecting a tool, we encourage researchers and clinicians to review the tool and evidence to support validity to determine the best fit for their population of focus and context of care.

- [Am I ON TRAC for Adult Care? Questionnaire](#)
- [Boston Children's Hospital ADAPT survey](#)
- [Self-Management Skills Assessment Guide](#)
- [Readiness for Transition \(RTQ\) Questionnaire](#) (kidney transplant recipients)
- [STAR_x Questionnaire](#)
- [Transition Readiness Assessment Questionnaire](#)
- [UNC TR_xANSITION Index](#)

Patient Name: _____ Date of Birth: ___/___/___ Today's Date ___/___/___ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes **your** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes **your** skill level. **Check here** if you are a parent/caregiver completing this form.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					



Patient Name		Date	
Medical Record #	Transition ID	Institution	

UNC TR_xANSITION Scale™ 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

		Correct	Non-specific	Does not know
1	What is the name of your health condition?	1.0	0.5	0.0
2	What physical symptoms do you experience because you have [name of health condition]?	1.0	0.5	0.0
3	How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T	_____ out of 3	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

R_x: Medications

		Can name all	Can name some	Cannot name any	N/A
4	What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition?	1.0	0.5	0.0	
5	When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
6	What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
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?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal R _x	_____ out of _____		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion R _x			

Adherence

		Yes	Sometimes	No	N/A
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?	0.0	0.5	1.0	
9	Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0	
10	Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal A		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion A			

Nutrition

		Knows definitely	Has an idea	Does not know	
11	When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	1.0	0.5	0.0	
12	Are you supposed to follow any special diet because you have [name of health condition]?	1.0	0.5	0.0	
13	<i>[if the patient is on a special diet]</i> What are examples of the foods and/or drinks that you should have more or less of?	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>		Subtotal N		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N			

Self-management skills

		Yes	Sometimes	No	N/A
14	Do you usually remember to take your medicines on your own?	1.0	0.5	0.0	
15	Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0	
16	Do you usually call in your prescription refills yourself?	1.0	0.5	0.0	
17	Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18	Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19	Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20	<i>[if the patient has medical procedures to perform]</i> Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal S		____ out of ____	
<i>Divide the subtotal by the number of applicable questions</i>		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

		Knows definitely	Has an idea	Does not know	
21	Would your health condition likely affect your ability to: <i>[if female]</i> become pregnant? <i>[if male]</i> get someone pregnant?	1.0	0.5	0.0	
22	<i>[Females only]</i> What are risks you might face if/when you become pregnant because you have [name of health condition]?	1.0	0.5	0.0	N/A
23	<i>[Females only]</i> Do you take any medicines that would be harmful to an unborn baby if you became pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD's?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I			
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			
		Male		____ out of 2	
		Female		____ out of 4	

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

Trade / School

		Knows definitely	Has an idea	Does not know
25	What are your future plans in regards to school and/or a job?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T		_____ out of 1
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

Insurance

		Knows definitely	Has an idea	Does not know	
26	What is health insurance and why is it important to have?	1.0	0.5	0.0	
27	What is the name of your current health insurance provider?	1.0	0.5	0.0	
28	[If he/she is currently insured] At what age will your current health insurance coverage end?	1.0	0.5	0.0	N/A
29	How can you get health insurance coverage for yourself when you are an adult?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I		_____ out of _____	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			

Ongoing support

		Self	Parents/friends	Does not know
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?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal 0		_____ out of 1

New health care providers

		Knows definitely	Has an idea	Does not know
31	When it comes time for you to switch to an adult doctor, how will you find one?	1.0	0.5	0.0
32	In order to get your medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal N	_____ out of 2	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N		

Raw total score	<i>Sum all section subtotals here (max 32)</i>	
T.R_xA.N.S.I.T.I.O.N Score™	<i>Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)</i>	

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

Patient Name		Date	
Medical Record #	Transition ID	Institution	

UNC TR_xANSITION Scale™ for Adult Patients:

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

		Correct	Non-specific	Does not know
1	What is the name of your health condition?	1.0	0.5	0.0
2	What physical symptoms do you experience because you have [name of health condition]?	1.0	0.5	0.0
3	How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T	_____ out of 3	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

R_x: Medications

		Can name all	Can name some	Cannot name any	N/A
4	What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition?	1.0	0.5	0.0	
5	When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
6	What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
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?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal R _x	_____ out of _____		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion R _x			

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Adherence

		Yes	Sometimes	No	N/A
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?	0.0	0.5	1.0	
9	Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0	
10	Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal A		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion A			

Nutrition

		Knows definitely	Has an idea	Does not know	
11	When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	1.0	0.5	0.0	
12	Are you supposed to follow any special diet because you have [name of health condition]?	1.0	0.5	0.0	
13	<i>[if the patient is on a special diet]</i> What are examples of the foods and/or drinks that you should have more or less of?	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>		Subtotal N		___ out of ___	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N			

Self-management skills

		Yes	Sometimes	No	N/A
14	Do you usually remember to take your medicines on your own?	1.0	0.5	0.0	
15	Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0	
16	Do you usually call in your prescription refills yourself?	1.0	0.5	0.0	
17	Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18	Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19	Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20	<i>[if the patient has medical procedures to perform]</i> Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal S	____ out of ____		
<i>Divide the subtotal by the number of applicable questions</i>		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

		Knows definitely	Has an idea	Does not know	
21	Would your health condition likely affect your ability to: <i>[if female]</i> become pregnant? <i>[if male]</i> get someone pregnant?	1.0	0.5	0.0	
22	<i>[Females only]</i> What are risks you might face if/when you become pregnant because you have [name of health condition]?	1.0	0.5	0.0	N/A
23	<i>[Females only]</i> Do you take any medicines that would be harmful to an unborn baby if you became pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD's?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I			
		Male	____ out of 2		
		Female	____ out of 4		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			

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Trade / School

		Knows definitely	Has an idea	Does not know
25	What are your future plans in regards to school and/or a job?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T		_____ out of 1
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

Insurance

		Knows definitely	Has an idea	Does not know	
26	What is health insurance and why is it important to have?	1.0	0.5	0.0	
27	What is the name of your current health insurance provider?	1.0	0.5	0.0	
28	[If he/she is currently insured] At what age will your current health insurance coverage end?	1.0	0.5	0.0	N/A
29	How can you get health insurance coverage for yourself?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal I		_____ out of _____	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion I			

Ongoing support

		Self	Parent/ friend/ partner	Does not know
30	Who manages your health condition, for example calls in prescription refills, picks up meds from pharmacy, and makes doctor appointments?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal O		_____ out of 1

New health care providers

		Knows definitely	Has an idea	Does not know
31	If you need to switch to a new doctor, how will you find one?	1.0	0.5	0.0
32	In order to get your medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal N	_____ out of 2	
<i>Divide the subtotal by the number of applicable questions</i>		Proportion N		

Raw total score	<i>Sum all section subtotals here (max 32)</i>	
T.R_xA.N.S.I.T.I.O.N Score™	<i>Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)</i>	

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