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

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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

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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

<table>
<thead>
<tr>
<th>Name of clinical program / health plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>State of participating clinical program / health plan</td>
</tr>
<tr>
<td>Patient or Member ID</td>
</tr>
<tr>
<td>Name of patient</td>
</tr>
<tr>
<td>Gender of patient</td>
</tr>
<tr>
<td>Date of birth</td>
</tr>
<tr>
<td>Home address</td>
</tr>
<tr>
<td>PMCA chronic condition category: Non-complex chronic, Complex chronic*</td>
</tr>
<tr>
<td>PMCA-identified body system(s)*</td>
</tr>
<tr>
<td>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)</td>
</tr>
<tr>
<td>Length (in months) of continuous enrollment (ignoring gaps ≤45 days)*</td>
</tr>
</tbody>
</table>

*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.

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

<table>
<thead>
<tr>
<th>Goal</th>
<th>300 completed surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicted response rate</td>
<td>20 percent (=.2)</td>
</tr>
<tr>
<td>Minimum total sample size</td>
<td>(300/.2)=1500 per health system</td>
</tr>
</tbody>
</table>

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

Q4: In the last 12 months, did you talk with this provider without your parent or guardian in the room?

Response = Yes → Assign score of 1 for Question 4.

Response = No → Assign score of 0 for Question 4.

Q5: In the last 12 months, did you and this provider talk about you being more in charge of your health?

Response = Yes → Assign score of 1 for Question 5.

Response = No → Assign score of 0 for Question 5.

Q6 and Q7 are evaluated together as if they are a single question. (Q67=0 or 1)

Q6: 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?

Q7: In the last 12 months, how often did you schedule your own appointments with this provider?

Q6 = Yes and Q7 = Sometimes, Usually, or Always OR Q6 = Yes and Q7 = Never OR Q6 = No and Q7 = Sometimes, Usually, or Always

Q6 Response = No AND Q7 Response = Never

Assign score of 1 for Q67.

Assign score of 0 for Q67.

Q8: In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?

Response = Yes → Assign score of 1 for Question 8.

Response = No → Assign score of 0 for Question 8.
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 $X_{Qi} = 1$ when question score = 1
  $= 0$ otherwise
  $Y_{Qi} = 1$ when question has a score (0 or 1)
  $= 0$ otherwise

  $P_Q = \frac{\sum X_{Qi}}{\sum Y_{Qi}}$

- 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

Q9: In the last 12 months, did you take any prescription medicine?

Q11: In the last 12 months, were you prescribed any medicine to take every day for at least a month?

Response to Question 9 = yes

AND

Response to Question 11 = yes

Assign scores for Questions 10, 12, and 13, which together comprise Composite 2.

Response to Question 9 = No

OR

Response to Question 11 = No

Score is not calculated for respondent for Composite 2.

Q10: In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?

Response = Sometimes, Usually or Always

Assign score of 1 for Question 10.

Response = Never

Assign score of 0 for Question 10.

Q12: In the last 12 months, did you and this provider talk about remembering to take your medicines?

Response = Yes

Assign score of 1 for Question 12.

Response = No

Assign score of 0 for Question 12.

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 = Yes

Assign score of 1 for Question 13.

Response = No

Assign score of 0 for Question 13.
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:

\[
P_Q = \frac{\sum X_{Q_i}}{\sum Y_{Q_i}}
\]

- 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

Q15: 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?

- **Response = Yes**
  - Assign score of 1 for Question 15.
- **Response = No**
  - Assign score of 0 for Questions 15, 16, 17, and 18.

Q16: 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?

- **Response = Yes**
  - Assign score of 1 for Questions 16.
- **Response = No**
  - Assign score of 0 for Questions 16.

Q17: 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?

- **Response = Yes**
  - Assign score of 1 for Question 17.
- **Response = No**
  - Assign score of 0 for Questions 17 and 18.

Q18: Did this provider give you this plan in writing?

- **Response = Yes**
  - Assign score of 1 for Questions 18.
- **Response = No**
  - Assign score of 0 for Questions 18.

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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:
  \[ P_Q = \frac{\sum X_{Q_i}}{\sum Y_{Q_i}} \]
  \[
  \begin{align*}
  X_{Q_i} &= 1 \text{ when question score} = 1 \\
  &= 0 \text{ otherwise} \\
  Y_{Q_i} &= 1 \text{ when question has a score (0 or 1)} \\
  &= 0 \text{ otherwise}
  \end{align*}
  \]
- Calculate the overall composite proportion (CP) for the domain:
  - Calculate P15, P16, P17, and P18
  - Calculate \((P_{15}+P_{16}+P_{17}+P_{18})/4 = CP_3\)
- Calculate the Composite Score (CS) for the domain:
  - \(CP_3 \times 100 = CS_3\)
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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.
References


### 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

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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 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

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 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.
ADAPT survey: Health Plan

**TUS EXPERIENCIAS CON LA ATENCIÓN MÉDICA**

**INSTRUCCIONES**
Contesta todas las preguntas marcando el cuadrito 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 ____________________

(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

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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
    - Siembre

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

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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.
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?

☐ Sí
☐ No, mi proveedor principal es__________

(Copia de la cinta)

(2. 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 → Sí 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

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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?
- No, ni de origen hispano, ni latino, ni español
- Sí, de origen mexicano, mexicano-american o 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

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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

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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 cuadrito 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,

xxxxxxxxxx, MD

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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 entregúesela 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 cuadrito 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,

xxxxxxxxxx, MD

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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 no 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 questions(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 questions(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 questions 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.”