



Pediatric Integrated Care Survey 1.0

User Manual

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The team also included Sonja Ziniel, PhD MA, Sara Singer, PhD MBA, and Hannah Rosenberg, MSc.



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I. Introduction

This Manual is intended to assist users of the Pediatric Integrated Care Survey (PICS) to optimally adapt and employ the instrument. The Pediatric Integrated Care Survey was developed to measure the family-reported experience of care integration of child health, broadly defined. The outcomes are intended to inform quality improvement efforts

The Pediatric Integrated Care Survey is freely available in the public domain, and it is copyrighted by Boston Children's Hospital. So that we may track the implementation experience of the PICS instrument, we respectfully request that prospective PICS users contact the PICS team before implementing the tool:

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II. General Information about the Pediatric Integrated Care Survey (PICS)

PICS is an instrument that measures the outcome of family-reported experience of integrated care for child health. Families have been essential partners in this work, from conception, to design, to testing, and pilot implementation.

The study team invited parents and guardians to participate in focus groups and cognitive interviews. These qualitative data collection processes assisted in determining the question content and structure. Once the pilot survey was finalized, the team implemented the administration of the survey in a pilot study and successfully validated a core set of questions through the process of factor analysis.

Survey respondents in the pilot study were actively recruited from July, 2014 to June, 2015, relying on collaborative efforts with family advocacy organizations, ambulatory primary and subspecialty care settings, and a school for children and youth with special health care needs. The pilot survey results were analyzed and validated through test-retest reliability and through factor analysis. The end product is a core set of validated "rating" questions, as well as accompanying demographic and health care status questions, a set of supplementary questions, and five topic-specific modules.



III. Adaptation and Implementation for individual use

Adaptation:

In the Pediatric Integrated Care Survey, the questions are structured so that they ask about the overall experiences of the family across the continuum of care, not just relating to care in a single location of a single point in time. We began by building off the definition of integrated care promoted by Singer, et al¹: “care that is coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients’ needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health.” We adapted to account for child health perspective: “Integrated Care is the seamless provision of health care services, from the perspective of the patient and family, across entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries”^{2,3}.

In an effort to understand the experiences *across the care continuum*, the questions all begin with: “In the past 12 months” and ask about “your child’s care team members”. We recommend that you take into consideration the question introduction, and modify the time frame and subject(s) in the question based on the factors you are measuring in your setting. Please see example question below.

[Example Question]

PICS Core question #33

We would recommend adapting the items in brackets below and keeping the other content the same to keep fidelity to the validated assessment tool. Please note: the questions were validated with the 12 month time frame, but a shorter time frame has been used in local administration.

CORE QUESTION

33.) [In the past 12 months], how often have your [child’s care team members] talked with you about how health care decisions for your child will affect your whole family?

EXAMPLE ADAPTATION

33.) [In the past 6 months], how often have your [child’s care team members in the “Smith Primary Care Clinic”] talked with you about how health care decisions for your child will affect your whole family?

Implementation: In our pilot study, we administered the survey both by email and mail. Our recommendation is to offer respondents both options to yield the highest response rate. We also implemented a process of reminder calls/emails which we found to be helpful.



Mail Survey: In the pilot phase, we mailed a paper copy of the survey with a prepaid return envelope.

Web-based Survey: In the pilot phase, we created an electronic data capture form and emailed it to participants. We recommend that the web-based versions are tested multiple times before finalized as web-based surveys are more difficult to identify errors in skip patterns.

PICS is intended to be used both to test effectiveness of an intervention by administering the tool pre and post intervention and to inform areas that need improvement from perspective of family (by administering the tool once). In our next phase of work, we will be testing usability/feasibility of the PICS instrument.

IV. Specific Tools

A. Core Instrument

The Core PICS Instrument includes a set of 19 validated rating questions. These questions were validated through the process of test-retest reliability and factor analysis. Exploratory factor analysis (EFA) was used to determine which of the experience items were included in the final questionnaire and the underlying measurement domains they represented. Psychometric properties of the final questionnaire were evaluated through assessment of construct validity, concurrent criterion validity, internal consistency, and test-retest reliability.

The core instrument also includes a set of health care /health status and demographic questions. These questions capture demographic information in addition to respondent reported data on the child's health status and utilization of services. This section also includes questions that ask the respondent to indicate the number and types of providers their child has seen in the past year and to indicate the specialty departments, regardless of institutional affiliation, that have been involved in their child's care. We expect that when PICS is used in a clinic setting, the providers will already have much of this information documented in the chart. We recommend that PICS users review the suggested health care/health status and demographic questions and select the items that are valuable to collect for their purposes. When PICS is administered for quality improvement purposes, we urge PICS users to consider what information they already have access to in order to avoid survey burden.



The validated rating questions in the core instrument are the following; split into 5 factors

Core with 19 questions, 5 factors

1.) Access to care [2 questions: 1.17; 1.18]

17.) In the past 12 months, how often did you have difficulties or delays getting medical or social services for your child because there were waiting lists, backlogs, or other problems getting appointments? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

18.) In the past 12 months, how often did you have difficulties or delays getting medical or social services for your child because you had trouble getting the information you needed? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

2.) Care goal creation/planning [2 questions: 1.30; 1.31]

30.) In the past 12 months, have your child's care team members created short-term care goals, meaning goals up to 6 months in the future? (*Check ONE box*)

- Yes
- No

31.) In the past 12 months, have your child's care team members created long-term care goals, meaning goals 6 months or longer into the future? (*Check ONE box*)

- Yes
- No



3.) Family impact – 5 questions [1.33; 1.34; 1.35; 1.36; 1.37]

33.) In the past 12 months, how often have your child's care team members talked with you about how health care decisions for your child will affect your whole family?

(Check ONE box)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

34.) In the past 12 months, how often have your child's care team members talked to you about things in your life that cause you stress because of your child's health or care needs? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

35.) In the past 12 months, how often have your child's care team members talked to you about things that make it hard for you to take care of your child's health? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

36.) In the past 12 months, how often have your child's care team members offered to communicate with you in ways other than an in-person visit, such as phone, email, skype or telehealth, if no physical examination was necessary? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always



37.) In the past 12 months, how often have your child's care team members offered you opportunities to connect with other families who they thought might be of help to you? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

4.) Communication between HCP (Health Care Provider) and parent [4 questions: 1.22; 1.24; 1.25; 1.32]

22.) In the past 12 months, how often did your child's care team members explain things in a way that you could understand? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

24.) In the past 12 months, how often did you feel comfortable letting your child's care team members know that you had any concerns about your child's health or care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not have any concerns

25.) In the past 12 months, how often did you feel that your child's care team members listened carefully to what you had to say about your child's health and care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always



32.) In the past 12 months, how often have your child's care team members treated you as a full partner in the care of your child? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

5.) Team functioning/performance/quality/connectivity [6 questions: 1.13; 1.23; 1.26; 1.27; 1.28; 1.29]

13.) In the past 12 months, did all of your child's medical providers have access to the same medical records?

(*Check ONE box*)

- Yes
- No

23.) In the past 12 months, how often did you feel that your child's care team members knew about the advice you got from your child's other care team members? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

26.) In the past 12 months, how often has someone on your child's care team explained to you who was responsible for different parts of your child's care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always



27.) In the past 12 months, how often did you feel that your child's care team members were aware of all tests and evaluations your child has had recently in order to avoid unnecessary testing? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don't know

28.) In the past 12 months, how often did you feel that your child's care team members followed through with their responsibilities related to your child's care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don't know

29.) In the past 12 months, how often have you felt that your child's care team members thought about the "big picture" when caring for your child, meaning dealing with all of your child's needs? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

B. Supplementary Questions

These are a set of 15 rating questions divided into 3 topic areas. Due to sample size limitations, we were not able to validate these in our initial phase of testing, but we believe these questions still provide important information based on qualitative data collection. We will be tracking the experience of further testing of these questions with the aim of including them in subsequent factor analyses.

➤ **Suggestions for using supplementary questions:**

If there are items in the set of supplementary questions that would be valuable to measure in your setting, we would encourage you to add them to the core instrument. In the question chart on page 27, you will see the Version 1.0 instrument questions numbers and their corresponding pilot survey question numbers. We would encourage you to add the supplementary questions in order of how they appeared in the pilot instrument in order to achieve content cohesion of your survey.

The supplementary question topics are:

1. Adapting to Changes [3 questions: S1.1; S1.2; S1.3]

1.) In the past 12 months, how often have your child's care team members modified your child's care based on changes in your child's condition or health? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not have any changes in his/her condition or health

2.) In the past 12 months, how often have your child's care team members worked with you and your family to adapt to modifications in your child's care?(*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no modifications in my child's care



3.) In the past 12 months, how often has someone on your child's care team worked with you to plan for your child's health care when there have been big changes in your child's life? (Examples: child enters daycare, begins or finishes school, a new sibling is born, family moves) (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no big changes in my child's life

2. Connecting to Resources (A. General and School/B. Community/State Resources) [A- 3 questions: S1.4; S1.5; S1.6 and B- S1.7; S1.8; S1.9; S1.10]

A. General and School

4.) In the past 12 months, how often has someone on your child's care team given you resources you needed so that your family could be more independent in caring for your child? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not need any resources to be able to care more independently for my child

5.) In the past 12 months, how often did your child's care team members support you in getting additional resources that your child needed? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not need additional resources



6.) In the past 12 months, how often have your child's care team members helped you to get more services at home to take care of your child's health if you needed them? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not need more services at home

B. School, Community and State

7.) In the past 12 months, how often did you feel that someone on your child's care team gave you enough information about schools or child care centers? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not want or need information about schools or child care centers

8.) In the past 12 months, how often did you feel that someone on your child's care team gave you enough information about state or community organizations, such as Early Intervention, Head Start, Family to Family Support, Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI)? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not need information about state or community organizations

9.) In the past 12 months, how often have your child's care team members made sure that you understood ways to help pay for things that insurance doesn't cover? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- Insurance covers all costs for my child's care



10.) In the past 12 months, how often have your child's care team members helped you make contact with community services when you needed them (for example, special education, recreation, after-school programs, family support services, respite care)? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not need community resources

3. Enhancing Communication: [5 questions: S1.11; S1.12; S1.13; S1.14; S1.15]

11.) In the past 12 months, how often did you feel that your child's care team members talked to each other in person, by phone or by email when you thought that direct communication between them was important for your child's care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not need community resources
- I don't know

12.) In the past 12 months, how often have you had to repeat information about important events in your child's life or important details about your child's health that you thought care team members should have known? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always



13.) In the past 12 months, did your child's care team members have any team meetings that team members attended either in person or over the phone? (*Check ONE box*)

- Yes
- No, but I would have liked this to happen
- No, but I don't think these team meeting are necessary for my child's care

14.) In the past 12 months, how often have your child's care team members changed care instructions

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- It was not necessary to change care instructions

15.) In the past 12 months, how often have your child's care team members found different ways to explain things about your child's medical care to you (such as drawing a picture, showing you a video) if you did not understand their words because they were too technical or because of language barriers? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- This was not necessary

Topic Specific Modules

We believe the questions included in the topic specific modules are valuable, since they reflect input from our family partners and focus groups. Similarly to the Supplementary Questions, due to sample size limitations in our initial implementation work, we were not able to validate these questions. We will be tracking the experience of further testing of these questions with the aim of including them in subsequent factor analyses. Our recommendation is that PICS users choose modules that relate to improvements that they are focusing on in their setting. For instance, select the "Care Plan" module if care planning is a focus of the testing institution's work and you believe respondents should be able to report on their experiences with care planning as opposed to a setting in which the majority of respondents would not have had experiences with a care plan. We recommend, if using the modules, they are added after the core set of questions and before the demographic information.



Brackets: Please review the following for instructions:

If there is a bracket at the end of a response option, it means that, based on the respondent's answer, they are not able to answer the remainder of the module questions for that particular module. We recommend that the bracket either has the following information: "Please skip to the end of this module" or, if you choose to combine question sets, "Please go to question...." and insert the next question in the following set.

EXAMPLE:

In Module 1, "Transition to Adult Care", the first question is "Is your child 13 years or older" [response options: yes/no]. Based on national standards⁴, it is recommended that 13 is the age to start discussing transition to adult care. Therefore if the respondent answers [no] then they are not eligible to answer the remaining questions in the module.

The module topics are:

1. Transition to Adult Care
2. Care Plan
3. Integrator
4. Burden
5. School and Services through Individualized Education Plan

Module 1: Transition to Adult Care [4 questions: M1_1.1; M1_1.2; M1_1.3; M1_1.4]

1.) Is your child 13 years or older?

- Yes → go to question [2]
- No → skip to question []

2.) In the past 12 months, have any of your child's care team members given you information about transferring your child to adult care? (*Check ONE box*)

- Yes
- No

3.) In the past 12 months, have any of your child's care team members talked to you about the process of transferring your child to adult care? (*Check ONE box*)

- Yes → go to question [4]
- No → skip to question []



4.) In the past 12 months, have any of your child's care team members talked with you about necessary steps to prepare your child to transfer to adult care? (*Check ONE box*)

- Yes
- No

Module 2: Care Plan [6 questions: M2_1.1; M2_1.2; M2_1.3; M2_1.4; M2_1.5; M2_1.6]

1.) In the past 12 months, how often have your child's care team members talked with you about specific goals for your child's health care? (*Check ONE box*)

- Never → skip to question []
- Rarely → skip to question []
- Sometimes → go to question [2]
- Usually → go to question [2]
- Almost Always → go to question [2]
- Always → go to question [2]

2.) In the past 12 months, has a member of your child's care team documented these goals in the form of a written care plan? (*Check ONE box*)

- Yes → go to question [3]
- No → skip to question []

3.) Did you and/or your family members contribute to the content of this written care plan? (*Check ONE box*)

- Yes
- No

4.) In the past 12 months, was this written care plan easily accessible to you? (*Check ONE box*)

- Yes
- No

5.) Was this care plan written in a way that you could easily understand? (*Check ONE box*)

- Yes
- No

6.) In the past 12 months, has someone on your child's care team regularly updated this written care plan to reflect changes and progress? (*Check ONE box*)

- Yes
- No
- I don't know



Module 3: Integrator [13 questions: M3_1.1; M3_1.2; M3_1.3; M3_1.4; M3_1.5; M3_1.6; M3_1.7; M3_1.8; M3_1.9; M3_1.10; M3_1.11; M3_1.12; M3_1.13]

1.) In the past 12 months who on your child's care team usually made sure that other members of the care team knew about information related to your child's health or care? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

2.) In the past 12 months, did your child's care team members have any team meetings that team members attended either in person or over the phone? (*Check ONE box*)

- Yes→ if yes, go to question [3]
- No, but I would have liked this to happen→ skip to question [4]
- No, but I don't think these team meeting are necessary for my child's care→ skip to question [4]

3.) In the past 12 months, who on your child's care team usually planned these team meetings? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this



4.) In the past 12 months, who on your child's care team usually coordinated visits and treatments to make sure that your child achieved his/her care goals? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

5.) In the past 12 months, who on your child's care team usually made sure that members of the care team followed through on tasks in a timely manner and made sure that nothing fell through the cracks? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

*6.) In the past 12 months, have your child's care team members created short-term care goals, meaning goals up to 6 months in the future? (*Check ONE box*)

- Yes → go to question [7]
- No → skip to question [8]

7.) In the past 12 months, who on your child's care team usually tracked progress toward these short-term care goals? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this



*8.) In the past 12 months, have your child's care team members created long-term care goals, meaning goals 6 months or longer into the future? (*Check ONE box*)

- Yes → go to question [9]
- No → skip to question [10]

9.) In the past 12 months, who on your child's care team usually tracked progress toward these long-term care goals? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

10.) In the past 12 months, who on your child's care team usually thought about which treatments and care tasks were most important to do right now and which could wait until later (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

11.) In the past 12 months, who on your child's care team usually thought about care needs that your child might have in the future and made sure that they were taken care of instead of waiting until there was an actual problem? (*Check ONE box*)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this



12.) In the past 12 months, who on your child's care team usually made sure that the "big picture" was taken into account when decisions and recommendations were made about your child's care? (Check ONE box)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

13.) In the past 12 months, who has been your child's care team leader? (Check ONE box)

- Me
- Someone else in my family/family friend
- Primary Care Provider or Pediatrician
- Medical or Surgical Specialty Provider
- Home Health Care Provider
- Behavioral Health Care Provider
- Care Coordinator/Case Manager/Social Worker
- Other, specify: _____
- No one single person usually did this

*These questions are also included in the core set of questions.

Module 4: Burden [3 questions: M4_1.1; M4_1.2; M4_1.3]

1.) In the past 12 months, how many hours a week have you spent on average providing care related to your child's health? (Check ONE box)

- 2 up to 6 hours a week
- 6 up to 11 hours a week
- 11 or more hours a week

2.) In the past 12 months, did you or another adult in your family have to stop working or work less hours in order to care for your child? (Check ONE box)

- Yes
- No

3.) In the past 12 months, have you had trouble paying bills because of financial difficulties caused by your child's care needs? (Check ONE box)

- Yes
- No



Module 5: School and Services Through Individualized Education Plan [5 questions: M5_1.1; M5_1.2; M5_1.3; M5_1.4; M5_1.5]

1.) In the past 12 months, has your child attended school or received services through an individualized education plan? (*Check ONE box*)

- Yes → go to question [2]
- No → skip to question []

2.) In the past 12 months, how often have your child's care team members asked you if you needed help getting services at school or at other places where your child receives educational services? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

3.) In the past 12 months, how often have your child's care team members helped you if there were any problems with your child attending school or receiving services in school related to his/her health issues? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no problems with my child attending school or receiving services in school
- This does not apply to my child's educational situation

4.) In the past 12 months, how often have all of your child's care team members been aware of events related to your child's health or care happening at your child's school or where your child receives educational services? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don't know



5.) In the past 12 months, how often have your child's care team members who cared for your child outside of school asked you if you would like them to speak to your child's in-school care team members when there have been changes in your child's health or care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no care team members who cared for my child in school/this does not apply to my child's educational situation
- There were no changes in my child's health or care

➤ **Suggestions for using module and supplementary questions:**

Repeat questions:

Please note, there are a few questions that are included in both the core set of questions and also are repeated in the modules—in the modules, these have an asterisk next to them. These questions need to be included in the modules because they indicate the logic sequence that the respondent should follow.

The repeat questions in the CORE and MODULES are:

- (1) PICS Core Question 30 and Module 3 Question 6
- (2) PICS Core Question 31 and Module 3 Question 8

There is also a repeat question in the supplementary and module question sets for the same reason as listed above. We recommend that if PICS users are administering questions from both supplementary and module 3 that you only ask the question once.

The repeat questions in the SUPPLEMENTARY and MODULE questions are:

- (1) PICS Supplementary Question 13 and Module 3 Question 2



V. Question Sources

The following chart lists the questions in order of Version 1.0 Core, Supplementary and Modules 1-5. It also lists the corresponding question number in the PICS pilot survey and the question source, if the question originated in another survey or was adapted from language in another survey.

The surveys included are:

[A] "Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey version 4.0."

Developed by the CAHPS program at the U.S. Agency for Healthcare Research and Quality.

[<https://cahps.ahrq.gov>].

[B] "Family-Centered Care Assessment for Families (FCCA-F)" survey. Family Voices/National Center for Family Professional Partnerships, 2013.

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[D] "Patient Perceptions of Integrated Care" survey, Harvard School of Public Health. Retrieved from [<http://www.integratedpatientcare.org/the-survey.html>]. 2015.

[E] "Pediatric Inpatient Experience Survey". Boston Children's Hospital Program for Patient Safety and Quality (2008).

Question Group	Question Number (PICS 1.0)	Question Number (PICS Pilot)	Source
CORE	1.1	0.1	NS-CSHCN; CG-CAHPS
	1.2	0.2	NS-CSHCN; CG-CAHPS
	1.3	0.3	NS-CSHCN; CG-CAHPS
	1.4	0.4	adapted from CG-CAHPS,
	1.5	0.5	NS-CSHCN
	1.6	0.6	adapted from NS-CSHCN
	1.7	0.7	adapted from NS-CSHCN
	1.8	0.8	
	1.9	0.9	NS-CSHCN
	1.10	0.10	NS-CSHCN
	1.11	0.11	NS-CSHCN
	1.12	0.12	
	1.13	0.13	
	1.14	0.14	NS-CSHCN ; CG-CAHPS
	1.15	0.15	NS-CSHCN
	1.16	0.16	adapted from NS-CSHCN
	1.17	0.17	NS_CSHCN
	1.18	0.18	NS_CSHCN
	1.19	0.19	
	1.20	0.20	
	1.21	0.21	
	1.22	0.22	CG CAHPS; PIES
	1.23	0.23	
	1.24	0.24	adapted FCCA-F
	1.25	0.25	
	1.26	0.29	
	1.27	0.34	
	1.28	0.35	
	1.29	0.45	
	1.30	0.58	
	1.31	0.60	

Question Group	Question Number (PICS 1.0)	Question Number (PICS Pilot)	Source
	1.32	0.66	adapted from NS-CSHCN
	1.33	0.67	FCCA-F
	1.34	0.72	PPIC
	1.35	0.73	PPIC
	1.36	0.74	
	1.37	0.79	adapted from FCCA-F
	1.38	0.85	
	1.39	0.86	PIES
	1.40	0.87	PIES
	1.41	0.88	PIES
	1.42	0.89	PIES
	1.43	0.90	NSCSHCN
	1.44	0.91	adapted from NSCSHCN/PIES
	1.45	0.92	NSCSHCN/U.S. Census Bureau, 2011
	1.46	0.93	
	1.47	0.94	
	1.48	0.95	
Supplementary	S1.1	0.36	
	S1.2	0.37	
	S1.3	0.38	FCCA-F
	S1.4	0.43	
	S1.5	0.44	
	S1.6	0.75	PPIC
	S1.7	0.26	
	S1.8	0.27	
	S1.9	0.76	FCCA-F
	S1.10	0.77	adapted from FCCA-F
	S1.11	0.32	

Question Group	Question Number (PICS 1.0)	Question Number (PICS Pilot)	Source
	S1.12	0.33	
	S1.13	0.54	
	S1.14	0.68	
	S1.15	0.78	
Module 1	M1_1.1	0.39	
	M1_1.2	0.40	
	M1_1.3	0.41	
	M1_1.4	0.42	
Module 2	M2_1.1	0.46	
	M2_1.2	0.47	
	M2_1.3	0.48	
	M2_1.4	0.49	
	M2_1.5	0.50	
	M2_1.6	0.51	
Module 3	M3_1.1	0.53	
	M3_1.2	0.54	
	M3_1.3	0.55	
	M3_1.4	0.56	
	M3_1.5	0.57	
	M3_1.6	0.58	
	M3_1.7	0.59	
	M3_1.8	0.60	
	M3_1.9	0.61	
	M3_1.10	0.62	
	M3_1.11	0.63	
	M3_1.12	0.64	
	M3_1.13	0.65	
Module 4	M4_1.1	0.69	adapted from NS-CSHCN

Question Group	Question Number (PICS 1.0)	Question Number (PICS Pilot)	Source
	M4_1.2	0.70	adapted from NS-CSHCN
	M4_1.3	0.71	adapted from NS-CSHCN
Module 5	M5_1.1	0.80	adapted from PPIC
	M5_1.2	0.81	
	M5_1.3	0.82	
	M5_1.4	0.83	
	M5_1.5	0.84	



VI. Scoring

We recommend that responses be scored as described below. The scoring method follows the methodology that is used to calculate composite scores of the CAHPS® survey tools. The response scale of each of the 19 rating items included in the PICS score instrument can be scored as “boxes”, such as top-box, top-2-box, bottom-box, or bottom-2-box. The composite scores represent proportional scores and their calculation using the “boxes” follows 4 steps.

- 1) Identification of eligible items
- 2) Generation of box scores
- 3) Summation of box scores across all eligible items representing each construct
- 4) Calculation of the composite score for each construct

The 19 rating items can be divided into positively (1.13, 1.22-1.37) and negatively phrased items (1.17 and 1.18). At this stage, we used the top-2-box approach for reporting but the top-box and bottom-box approach can be used as well. When reporting results, the scoring method should be indicated. Box scoring of items includes the generation of a new binary item with 1 indicating that the respondent chose the response option equivalent to the top- or bottom-box, or the response options equivalent to the top-2-box or bottom-2-box approach. The percentage of items that were scored in the “box” among all eligible items within each construct represents the composite score and varies between 0 and 100. Below we describe the calculation of composite scores and then provide an example calculation for 4 respondents and the construct “Team Functioning”.

Step 1: Identification of eligible items

Items are eligible to be included in the composite score calculation when they are answered by checking off 1 response option as provided in the response scale. An item becomes ineligible if respondents did not check off any response option for an item (missing value). For mail surveys, items also become ineligible if someone checks more than one response option or if someone puts their checkmark between response options. Web survey software generally has the functionality to prevent the selection of more than one response option.

Step 2: Generation of box scores

When generating box scores each eligible response item is transformed into a binary variable and the respondent receives a box score of 1 indicating that the respondent checked the or one of the desirable answers (depending which approach is used); 0 indicates that the respondent checked another response option. Table 1 shows which response options for each item should be represented by a value of 1 and which by a value of 0 for each of the 4 box score approaches top-box, top-2-box, bottom-box, and bottom-2-box.



Step 3: Summation of box scores within each construct

For each construct, the number of eligible items answered by the respondent should be counted. As a next step all box scores for the eligible items should be summed up. The sum should be between 0 (all box scores are 0) and the number of eligible items (all box scores of the eligible items are 1).

Step 4: Calculation of the composite score

As a last step, the box score sum should be divided by the number of eligible items. The resulting number will be between 0 and 1 and should then be multiplied by 100.

Table 1: Response options to receive a box score of 1 by various box scoring approaches

Item	Top-Box	Top-2-Box	Bottom-Box	Bottom-2-Box
Positively Phrased Items				
1.13	Yes	Yes	No	No
1.22	Always	Almost Always Always	Never	Never Rarely
1.23	Always	Almost Always Always	Never	Never Rarely
1.24	Always I did not have any concerns	Almost Always Always I did not have any concerns	Never	Never Rarely
1.25	Always	Almost Always Always	Never	Never Rarely
1.26	Always	Almost Always Always	Never	Never Rarely
1.27	Always	Almost Always Always	Never I don't know	Never Rarely I don't know
1.28	Always	Almost Always Always	Never I don't know	Never Rarely I don't know
1.29	Always	Almost Always Always	Never	Never Rarely
1.30	Yes	Yes	No	No
1.31	Yes	Yes	No	No
1.32	Always	Almost Always Always	Never	Never Rarely
1.33	Always	Almost Always Always	Never	Never Rarely
1.34	Always	Almost Always Always	Never	Never Rarely
1.35	Always	Almost Always Always	Never	Never Rarely
1.36	Always	Almost Always Always	Never	Never Rarely
1.37	Always	Almost Always Always	Never	Never Rarely
Negatively Phrased Items				
1.17	Never	Never Rarely	Always	Almost Always Always
1.18	Never	Never Rarely	Always	Almost Always Always

Composite Score Calculation Example using Construct “Team Functioning” and Top-2-Box Scoring

The example below shows the answers of 4 hypothetical respondents to all items of the construct “Team Functioning”. Respondent A, B, and C answered all items in an eligible way and can use 6 eligible items for their composite score calculation. Respondent D, however, did not answer item 1.13 and can only use 5 eligible items. Using the top-2-box approach in Table 1, each of the answers was coded as either 1 or 0. The item was coded as 1 if the respondent checked a response option was designated to be desirable and receive a box score of 1 for the top-2-box approach. The box scores were then summed up for all eligible items in the construct “Team Functioning” by respondent. The last step was to divide the box score sum by the number of eligible items and multiply the result by 100.

Table 2: 4 example respondents for the items underlying the construct “Team Functioning”

Item	Respondent A	Respondent B	Respondent C	Respondent D
1.13	Yes – 1	No – 0	No - 0	
1.23	Always - 1	Usually - 0	Usually - 0	Sometimes - 0
1.26	Sometimes - 0	Almost Always - 1	Almost Always - 1	Rarely - 0
1.27	Never - 0	Almost Always - 1	I don't know - 0	Almost Always - 1
1.28	I don't know - 0	Always - 1	Always - 1	I don't know - 0
1.29	Usually - 0	Almost Always - 1	Almost Always - 1	Usually - 0
# of Eligible Items	6	6	6	5
Box Score Sum	2	4	3	1
Composite Score Calculation	$(2/6) * 100 = 33.3$	$(4/6) * 100 = 66.7$	$(3/6) * 100 = 50.0$	$(1/5) * 100 = 20.0$



VII. References

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[D] "Patient Perceptions of Integrated Care" survey, Harvard School of Public Health. Retrieved from [<http://www.integratedpatientcare.org/the-survey.html>]. 2015.

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