Care Coordination Measures Atlas

Appendix IV. Care Coordination Measure Instruments

This appendix contains copies of many of the individual measure instruments identified in the *Care Coordination Measures Atlas*, with contact information for the measure developer when available.

The appendix is a living resource. Additional information on various measures will be added in updates until the resource is as complete as possible.

Note that, because of copyright constraints, AHRQ has made no changes to the measures; they remain in the same form as they were provided to AHRQ by their developers.

Measure # 1: Assessment of Chronic Illness Care (ACIC)

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 2: ACOVE-2 Quality Indicators – Continuity and Coordination of Care

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 3: Coleman Measures of Care Coordination

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Eric A. Coleman, MD, MPH:
Director, Care Transitions Program
13199 East Montview Blvd, Suite 400
Aurora, Colorado 80045
P: (303) 724-2456. F: (303) 724-2486
Eric.Coleman@ucdenver.edu
www.caretransitions.org

Copyright Details:

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Additional Notes:

- The Coleman Measures of Care Coordination included an adaptation of a telephone self-report survey published originally in Flocke, SA. J Fam Pract 1997;45(1):64-75. At this time, permission to reprint that original survey has not been obtained. Only the portion of the Coleman Measures of Care Coordination for which we have permission to reprint follows this page.

Administrative Measures of Care Coordination

Care Coordination Administrative Claims and Pharmacy Data:

2. Number of different physicians involved with care_____.
3. Number of different prescribers involved with care_____.
4. Percent of changes in one or more chronic disease medications which resulted in a follow-up visit within 28 days_____.
5. Percent of missed ambulatory encounters which resulted in a follow-up visit within 28 days_____.
6. Percent of same-day ambulatory encounters which resulted in a follow-up visit within 28 days_____.

Measure # 4a: Consumer Assessment of Healthcare Providers and Systems (CAHPS) – Adult Primary Care 1.0

Contact Information:

- Contact the CAHPS Help Line at cahps1@ahrq.gov or 1-800-492-9261 with questions or comments about the content or implementation of CAHPS surveys, the use of CAHPS surveys for consumer reporting or quality improvement, events sponsored by the CAHPS User Network, or the usability of the CAHPS Web site.

Copyright Details:

- All CAHPS instruments are in the public domain, so there is no charge for using them and permission is not required. However, the CAHPS name is a registered trademark held by the Agency for Healthcare Research and Quality. Survey users must use the complete instrument in its approved format if they wish to represent their survey as a CAHPS survey. Using the CAHPS name can be an advantage for users because it assures their constituencies and business partners that their data meet the original validity and reliability standards reported by the CAHPS program and that they are comparable to data on other competing organizations from which consumers may be asked to choose.

Additional Notes:

- To learn more about using the CAHPS "Clinician and Group Survey" instruments, visit: https://www.cahps.ahrq.gov/content/products/CG/PROD_CG_CG40Products.asp?p=1021&s=213.

CAHPS® Clinician & Group Survey

Version: Adult Primary Care Questionnaire 1.0

Language: English

Response Scale: 4 points

Note regarding the Never-to-Always response scale: This questionnaire employs a four-point response scale – "Never/Sometimes/Usually/Always" – which is the standard scale for CAHPS surveys. An alternative six-point scale adds "Almost never" and "Almost always" to the response options. Questionnaires with the six-point scale are available for downloading at https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX6p.asp.

A version of the questionnaire with the six-point scale has been used by several early adopters of the survey; it is also the version that was endorsed by the National Quality Forum. The CAHPS Consortium is examining the performance of the two response scales in the context of this survey.

File name: 351a-4_AdultPrim_Eng_4pt_V1.doc
Last updated: October 8, 2009

Instructions for Front Cover

- Replace the cover of this document with your own front cover. Include a user-friendly title and your own logo.
- Include this text regarding the confidentiality of survey responses:

  Your Privacy is Protected. All information that would let someone identify you or your family will be kept private. {VENDOR NAME} will not share your personal information with anyone without your OK. Your responses to this survey are also completely **confidential**. You may notice a number on the cover of the survey. This number is used **only** to let us know if you returned your survey so we don't have to send you reminders.

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

  What To Do When You're Done. Once you complete the survey, place it in the envelope that was provided, seal the envelope, and return the envelope to [INSERT VENDOR ADDRESS].

  If you want to know more about this study, please call XXX-XXX-XXXX.

Instructions for Format of Questionnaire

Proper formatting of a questionnaire improves response rates, the ease of completion, and the accuracy of responses. The CAHPS team's recommendations include the following:

- If feasible, insert blank pages as needed so that the survey instructions (see next page) and the first page of questions start on the right-hand side of the questionnaire booklet.
- Maximize readability by using two columns, serif fonts for the questions, and ample white space.
- Number the pages of your document, but remove the headers and footers inserted to help sponsors and vendors distinguish among questionnaire versions.

Additional guidance is available in **Preparing a Questionnaire Using the CAHPS Clinician & Group Survey**:
https://www.cahps.ahrq.gov/cahpskit/files/32_CG_Preparing_a_Questionnaire.pdf

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Survey Instructions

Answer each question by marking the box to the left of 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 on page 1**
☐ No

Your Doctor

1. Our records show that you got care from the doctor named below in the last 12 months.

Name of doctor label goes here

Is that right?

1☐ Yes
2☐ No → **If No, go to #26 on page 4**

The questions in this survey booklet will refer to the doctor named in Question 1 as "this doctor." Please think of that doctor as you answer the survey.

2. Is this the doctor you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?

1☐ Yes
2☐ No

3. How long have you been going to this doctor?

1☐ Less than 6 months
2☐ At least 6 months but less than 1 year
3☐ At least 1 year but less than 3 years
4☐ At least 3 years but less than 5 years
5☐ 5 years or more

Your Care From This Doctor in the Last 12 Months

These questions ask about **your own** health care. Do **not** include care you got when you stayed overnight in a hospital. Do **not** include the times you went for dental care visits.

4. In the last 12 months, how many times did you visit this doctor to get care for yourself?

1☐ None → **If None, go to #26 on page 4**
2☐ 1 time
3☐ 2
4☐ 3
5☐ 4
6☐ 5 to 9
7☐ 10 or more times

5. In the last 12 months, did you phone this doctor's office to get an appointment for an illness, injury or condition that **needed care right away**?

1☐ Yes
2☐ No → **If No, go to #7**

6. In the last 12 months, when you phoned this doctor's office to get an appointment for **care you needed right away**, how often did you get an appointment as soon as you thought you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

7. In the last 12 months, did you make any appointments for a **check-up or routine care** with this doctor?

1☐ Yes
2☐ No → **If No, go to #9**

8. In the last 12 months, when you made an appointment for a **check-up or routine care** with this doctor, how often did you get an appointment as soon as you thought you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

9. In the last 12 months, did you phone this doctor's office with a medical question during regular office hours?

1☐ Yes
2☐ No → **If No, go to #11**

10. In the last 12 months, when you phoned this doctor's office during regular office hours, how often did you get an answer to your medical question that same day?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

11. In the last 12 months, did you phone this doctor's office with a medical question **after** regular office hours?

1☐ Yes
2☐ No → **If No, go to #13**

12. In the last 12 months, when you phoned this doctor's office **after** regular office hours, how often did you get an answer to your medical question as soon as you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

13. Wait time includes time spent in the waiting room and exam room. In the last 12 months, how often did you see this doctor **within 15 minutes** of your appointment time?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

14. In the last 12 months, how often did this doctor explain things in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

15. In the last 12 months, how often did this doctor listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

16. In the last 12 months, did you talk with this doctor about any health problems or concerns?

1☐ Yes
2☐ No → **If No, go to #18**

17. In the last 12 months, how often did this doctor give you easy to understand instructions about taking care of these health problems or concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

18. In the last 12 months, how often did this doctor seem to know the important information about your medical history?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

19. In the last 12 months, how often did this doctor show respect for what you had to say?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

20. In the last 12 months, how often did this doctor spend enough time with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

21. In the last 12 months, did this doctor order a blood test, x-ray or other test for you?

1☐ Yes
2☐ No → **If No, go to #23**

22. In the last 12 months, when this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

23. Using any number from 0 to 10, where 0 is the worst doctor possible and 10 is the best doctor possible, what number would you use to rate this doctor?

☐ 0 Worst doctor possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best doctor possible

Clerks and Receptionists at This Doctor's Office

24. In the last 12 months, how often were clerks and receptionists at this doctor's office as helpful as you thought they should be?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

25. In the last 12 months, how often did clerks and receptionists at this doctor's office treat you with courtesy and respect?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

About You

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

1☐ Excellent
2☐ Very good
3☐ Good
4☐ Fair
5☐ Poor

27. A health provider is a doctor, nurse or anyone else you would see for health care. In the past 12 months, have you seen a doctor or other health provider 3 or more times for the same condition or problem?

1☐ Yes
2☐ No → **If No, go to #29**

28. Is this a condition or problem that has lasted for at least 3 months? Do **not** include pregnancy or menopause.

1☐ Yes
2☐ No

29. Do you now need or take medicine prescribed by a doctor? Do **not** include birth control.

1☐ Yes
2☐ No → **If No, go to #31**

30. Is this medicine to treat a condition that has lasted for at least 3 months? Do **not** include pregnancy or menopause.

1☐ Yes
2☐ No

31. What is your age?

1☐ 18 to 24
2☐ 25 to 34
3☐ 35 to 44
4☐ 45 to 54
5☐ 55 to 64
6☐ 65 to 74
7☐ 75 or older

32. Are you male or female?

1☐ Male
2☐ Female

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

1☐ 8th grade or less
2☐ Some high school, but did not graduate
3☐ High school graduate or GED
4☐ Some college or 2-year degree
5☐ 4-year college graduate
6☐ More than 4-year college degree

34. Are you of Hispanic or Latino origin or descent?

1☐ Yes, Hispanic or Latino
2☐ No, not Hispanic or Latino

35. What is your race? Please mark one or more.

1☐ White
2☐ Black or African American
3☐ Asian
4☐ Native Hawaiian or Other Pacific Islander
5☐ American Indian or Alaskan Native
6☐ Other

36. Did someone help you complete this survey?

1☐ Yes
2☐ No → **Thank you.**
Please return the completed survey in the postage-paid envelope.

37. How did that person help you? Mark all that apply.

1☐ Read the questions to me
2☐ Wrote down the answers I gave
3☐ Answered the questions for me
4☐ Translated the questions into my language
5☐ Helped in some other way

Please print: _____

_____

_____

Thank you.

Please return the completed survey in the postage-paid envelope.

CAHPS® Clinician & Group Survey

Supplemental Items for the Adult Primary Care Questionnaire 1.0

Language: English

Response Scale: 4 points

File name: 351a-4_AdultPrim_Eng_4pt_V1.doc
Last updated: October 8, 2009

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Important instructions

Placing Supplemental Items in the Core Questionnaires. After you copy one or more supplemental items into the core questionnaire:

- **Fix the formatting** of the items as needed to fit into the two-column format.
- **Renumber** the supplemental item and **ALL** subsequent items so that they are consecutive.
- **Revise ALL skip instructions** in the questionnaire to make sure they point the respondent to the correct item number.

Definition of Specialist. If you choose to use one or more supplemental items that refer to specialists, please insert this definition before the first of these items: "Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care."

Addressing Health Literacy

Insert HL1 – HL4 after core question 14.
Please note that HL1 was formerly C3. C3 was part of the Provider Communication supplemental items but has been updated as part of the Item Set for Addressing Health Literacy.

HL1. In the last 12 months, how often were the explanations this doctor gave you hard to understand because of an accent or the way the doctor spoke English?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL2. In the last 12 months, how often did this doctor use medical words you did not understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL3. In the last 12 months, how often did this doctor talk too fast when talking with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL4. In the last 12 months, how often did this doctor use pictures, drawings, or models to explain things to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL5 – HL9 after core question 15.
Please note that HL5 was formerly C5.

HL5. In the last 12 months, how often did this doctor ignore what you told him or her?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL6. In the last 12 months, how often did this doctor interrupt you when you were talking?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Please note that HL7 was formerly C7.

HL7. In the last 12 months, how often did this doctor show interest in your questions and concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL8. In the last 12 months, how often did this doctor answer all your questions to your satisfaction?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL9. In the last 12 months, how often did this doctor give you all the information you wanted about your health?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL10 before core question 16.
Please note that HL10 was formerly C1.

HL10. In the last 12 months, how often did this doctor encourage you to talk about all your health problems or concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL11 – HL15 after core question 18.

HL11. In the last 12 months, did you see this doctor for a specific illness or for any health condition?

1☐ Yes
2☐ No → **If No, go to core question 19**

HL12. In the last 12 months, how often did this doctor give you easy to understand instructions about what to do to take care of this illness or health condition?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL13. In the last 12 months, how often did this doctor ask you to describe how you were going to follow these instructions?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL14. Sometimes doctors give instructions that are hard to follow. In the last 12 months, how often did this doctor ask you whether you would have any problems doing what you need to do to take care of this illness or health condition?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL15. In the last 12 months, how often did this doctor explain what to do if this illness or health condition got worse or came back?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL16 after core question 19.
Please note that HL16 was formerly C6.

HL16. In the last 12 months, how often did this doctor use a condescending, sarcastic, or rude tone or manner with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL17 – HL24 after core question 20.

HL17. In the last 12 months, how often did you feel this doctor really cared about you as a person?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL18. In the last 12 months, did this doctor prescribe any new medicines or change how much medicine you should take?

1☐ Yes
2☐ No → **If No, go to core question 21**

HL19. In the last 12 months, how often did this doctor give you easy to understand instructions about how to take your medicines?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL20. In the last 12 months, did this doctor explain the possible side effects of your medicines?

[1]☐ Yes
[2]☐ No → **If No, go to #HL22**

HL21. In the last 12 months, how often did this doctor explain the possible side effects of your medicines in a way that was easy to understand?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

HL22. In the last 12 months, other than a prescription, did this doctor give you written information or write down information about how to take your medicines?

[1]☐ Yes
[2]☐ No → **If No, go to #HL24**

HL23. In the last 12 months, how often was the written information you were given easy to understand?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

HL24. In the last 12 months, how often did this doctor suggest ways to help you remember to take your medicines?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

Insert HL25 after core question 22. Core items 21-22 must be used prior to HL25.

Core question 21. Did this doctor order a blood test, x-ray or other test for you?

[1]☐ Yes
[2]☐ No → **If No, go to core question 23**

Core question 22. When this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL25. In the last 12 months, how often were the results of your blood test, x-ray or other test easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL26 – HL30 after core question 23.

HL26. In the last 12 months, did you have to fill out or sign any forms at this doctor's office?

1☐ Yes
2☐ No → **If No, go to core question 24**

HL27. In the last 12 months, how often did someone explain the purpose of a form before you signed it?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL28. In the last 12 months, how often were you offered help in filling out a form at this doctor's office?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL29. In the last 12 months, how often were the forms that you got at this doctor's office easy to fill out?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

After Hours E-Mail

Insert AE1 – AE2 after core question 12.

AE1. In the last 12 months, did you e-mail this doctor's office with a medical question?

[1]☐ Yes
[2]☐ No → **If No, go to core question 13**

AE2. In the last 12 months, when you e-mailed this doctor's office, how often did you get an answer to your medical question as soon as you needed?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

Being Kept Informed About Appointment Start

Insert KI1 after core question 13. In core question 13, add instruction at the "Always" response to skip over KI1 to core question 14.

KI1. In the last 12 months, after you checked in for your appointment at this doctor's office, were you ever kept informed about how long you would need to wait for your appointment to start?

[1]☐ Yes
[2]☐ No

Cost of Care (Prescriptions)

Insert COC1 – COC3 after core question 20.

COC1. In the last 12 months, did you take any prescription medicine?

[1]☐ Yes
[2]☐ No → **If No, go to core question 21**

COC2. In the last 12 months, were you ever worried or concerned about the cost of your prescription medicine?

[1]☐ Yes
[2]☐ No

COC3. In the last 12 months, did you and this doctor talk about the cost of your prescription medicine?

[1]☐ Yes
[2]☐ No

Cost of Care (Tests)

Insert COC4 – COC5 after core question 22.

COC4. In the last 12 months, were you ever worried or concerned about the cost of your blood tests, x-rays or other tests?

[1]☐ Yes
[2]☐ No

COC5. In the last 12 months, did you and this doctor talk about the cost of your blood tests, x-rays or other tests?

[1]☐ Yes
[2]☐ No

Doctor Role

Insert DR1 after core question 2.

DR1. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. Is this doctor a specialist?

[1]☐ Yes
[2]☐ No

Doctor Thoroughness

Insert DT1 – DT2 before core question 21.

DT1. In the last 12 months did this doctor ever examine you?

[1]☐ Yes
[2]☐ No → **If No, go to core question 21**

DT2. In the last 12 months, how often was this doctor as thorough as you thought you needed?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

Health Improvement

(Use only if sample will include elderly or individuals with chronic conditions.)

Insert HI1 after core question 17.

HI1. In the last 12 months, did you and this doctor talk about specific things you could do to prevent illness?

[1]☐ Yes
[2]☐ No

Health Promotion and Education

Insert HP1 – HP6 after core question 17. If HP1 – HP6 are used, patients who did not talk with their doctor about any health problems or concerns should skip to HP1; this requires a change in the skip instructions for core question 16. Note: If "Health Improvement" is included, HP1 – 6 follow HI1.

HP1. In the last 12 months, did you need this doctor's help in making changes to prevent illness?

1☐ Yes
2☐ No → **If No, go to question HP3**

HP2. In the last 12 months, did this doctor give you the help you needed to make changes to prevent illness?

1☐ Yes
2☐ No

HP3. In the last 12 months, did you and this doctor talk about a healthy diet and healthy eating habits?

1☐ Yes
2☐ No

HP4. In the last 12 months, did you and this doctor talk about the exercise or physical activity you get?

1☐ Yes
2☐ No

HP5. In the last 12 months, did you and this doctor talk about things in your life that worry you or cause you stress?

1☐ Yes
2☐ No

HP6. In the last 12 months, did this doctor ever ask you whether there was a period of time when you felt sad, empty or depressed?

1☐ Yes
2☐ No

Help With Problems or Concerns

Insert HPC1 after core question 16.

HPC1. Did this doctor help you with these problems or concerns?

1☐ Yes
2☐ No

Other Doctors and Providers at Your Doctor's Office

Insert OD1 – OD9 after core question 25. If this section is used, patients who had no visits with the sampled doctor should skip to OD1; this requires a change in the skip instructions for core question 4.

These questions ask about your experiences with other doctors and providers at this doctor's office. Please answer only for your own health care. Do not include dental care visits.

OD1. Sometimes when you go to this doctor's office, you might get care from another provider – for example, another doctor in the practice, a nurse, a nurse practitioner or a physician assistant.

In the last 12 months, were any of your appointments at this doctor's office with another doctor or other provider?

1☐ Yes
2☐ No → **If No, go to core question 26**

Please answer the following questions for the other doctors or providers you visited at this doctor's office.

OD2. In the last 12 months, how often did the other doctors or providers explain things in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

OD3. In the last 12 months, how often did the other doctors or providers listen carefully to you?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

OD4. In the last 12 months, did you talk with the other doctors or providers about any health problems or concerns?

[1]☐ Yes
[2]☐ No → **If No, go to question OD6**

OD5. In the last 12 months, how often did the other doctors or providers give you easy to understand instructions about what to do to take care of these health problems or concerns?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

OD6. In the last 12 months, how often did the other doctors or providers show respect for what you had to say?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

OD7. In the last 12 months, how often did the other doctors or providers spend enough time with you?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

OD8. In the last 12 months, how often did you feel that the other doctors or providers had all the information they needed to provide your care?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

OD9. Using any number from 0 to 10, where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all your health care from the other doctors or providers you visited at this doctor's office in the last 12 months?

☐ 0 Worst care possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best care possible

Provider Communication

Items C1, C3-C7 of the Provider Communication items have been updated and are now included in the Item Set for Addressing Health Literacy. This item set also includes additional items that address Provider Communication.

Insert C2 after core question 14. In core question 14, add instruction at the "Usually" and "Always" responses to skip over C2 to core question 15.

C2 was designed for and tested with a commercial health plan population using primarily a self-administered format. Item wording and format may not be appropriate for other modes of administration or other populations (e.g., Medicaid, Medicare, low literacy).

C2. In the last 12 months, were the explanations this doctor gave you about each of the following hard to understand?

	Yes	No	Does Not Apply
a) What was wrong with you?	1☐	2☐	3☐
b) The reason for a treatment?	1☐	2☐	3☐
c) What a medicine was for?	1☐	2☐	3☐
d) How to take a medicine?	1☐	2☐	3☐
e) Results of a blood test, x-ray or other test?	1☐	2☐	3☐
f) What to do if a condition got worse or came back?	1☐	2☐	3☐
g) Something else?	1☐	2☐	3☐

Please specify: _____

_____

Insert C8 before core question 21. If items SD1 – SD3 are used, C8 should follow SD3.

C8 and C9 were designed for and tested with a commercial health plan population using primarily a self-administered format. Item wording and format may not be appropriate for other modes of administration or other populations (e.g., Medicaid, Medicare, low literacy).

C8. In the last 12 months, during any of your visits, did this doctor:

	Yes	No	Does Not Apply
a) Listen to your reasons for the visit?	1☐	2☐	3☐
b) Show concern for your physical comfort?	1☐	2☐	3☐
c) Describe his or her physical findings?	1☐	2☐	3☐
d) Explain the reason for any additional tests?	1☐	2☐	3☐
e) Describe the next steps for your care or treatment?	1☐	2☐	3☐

Insert C9 before core question 21. If items SD1 – SD3 are used, C9 should follow SD3. If item C8 is used, C9 should follow C8.

C9. In the last 12 months, did this doctor give you complete and accurate information about:

	Yes	No	Does Not Apply
a) Tests?	1☐	2☐	3☐
b) Choices for your care?	1☐	2☐	3☐
c) Treatment?	1☐	2☐	3☐
d) Plan for your care?	1☐	2☐	3☐
e) Medications?	1☐	2☐	3☐
f) Follow-up care?	1☐	2☐	3☐

Provider Knowledge of Specialist Care

Insert PK1 – PK2 after core question 20.

Note: These items are recommended for use only if the sampled provider is not a specialist.

If C1 is included, insert PK1 – PK2 after C1.

Please refer to instructions at the front of this document about defining "specialists."

PK1. In the last 12 months, did this doctor suggest you see a specialist for a particular health problem?

1☐ Yes
2☐ No → **If No, go to core question 21**

PK2. In the last 12 months, how often did the doctor named in Question 1 seem informed and up-to-date about the care you got from specialists?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Recommend Doctor

Insert RC1 – RC2 after core question 23.

RC1. Would you recommend this doctor to your family and friends?

1☐ Definitely yes
2☐ Somewhat yes
3☐ Somewhat no
4☐ Definitely no

RC2. Please tell us how this doctor's office could have improved the care and services you received in the last 12 months.

_____

Shared Decision Making

Insert SD1 – SD3 before core question 21.

SD1. Choices for your treatment or health care can include choices about medicine, surgery, or other treatment. In the last 12 months, did this doctor tell you there was more than one choice for your treatment or health care?

1☐ Yes
2☐ No → **If No, go to core question 21**

SD2. In the last 12 months, did this doctor talk with you about the pros and cons of each choice for your treatment or health care?

1☐ Yes
2☐ No

SD3. In the last 12 months, when there was more than one choice for your treatment or health care, did this doctor ask which choice you thought was best for you?

1☐ Yes
2☐ No

Wait Time for Urgent Care

Insert WU1 after core question 6.

WU1. In the last 12 months, when you contacted this doctor's office to get an appointment for care you needed right away, how long did you usually have to wait between trying to get an appointment and actually seeing someone?

1☐ Same day
2☐ 1 day
3☐ 2-3 days
4☐ 4-7 days
5☐ 8-14 days
6☐ 15 days or longer

Your Care from Specialists in the Last 12 Months

Insert SC1 – SC8 after question 25. If this section is used, patients who have no visits with the sampled doctor should skip to SC1; this requires a change in the skip instructions at question 4.

Note: If "Other Doctors and Providers at Your Doctor's Office" items are included, change the skip at OD1 to SC1.

Please refer to instructions at the front of this document about defining "specialists."

These questions ask about **your own** health care. Do **not** include care you got when you stayed overnight in a hospital. Do **not** include the times you went for dental care visits.

SC1. In the last 12 months, did you try to make any appointments to see a specialist?

1☐ Yes
2☐ No → **If No, go to core question 26**

SC2. In the last 12 months, how often was it easy to get appointments with specialists?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

SC3. In the last 12 months, did you and this doctor talk about the cost of seeing a specialist?

1☐ Yes
2☐ No

SC4. In the last 12 months, were you ever worried or concerned about the cost of seeing a specialist?

1☐ Yes
2☐ No

SC5. How many specialists have you seen in the last 12 months?

[1]☐ None → **If None, go to core question 26**
[2]☐ 1 specialist
[3]☐ 2
[4]☐ 3
[5]☐ 4
[6]☐ 5 or more specialists

SC6. In the last 12 months, how often did the specialists you saw seem to know the important information about your medical history?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

SC7. We want to know your rating of the specialist you saw most often in the last 12 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate that specialist?

☐ 0 Worst specialist possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best specialist possible

SC8. Was the specialist you saw most often in the last 12 months the doctor named in Question 1?

[1]☐ Yes
[2]☐ No

Your Most Recent Visit

Insert RV1 – RV11 after core question 25.

These questions ask about your most recent visit with this doctor. Please answer only for your own health care.

RV1. During your most recent visit with this doctor, were you kept informed about how long you would need to wait for your appointment to start?

1☐ Yes
2☐ No

RV2. Wait time includes time spent in the waiting room and exam room. During your most recent visit with this doctor, did you see this doctor **within 15 minutes** of your appointment time?

1☐ Yes
2☐ No

RV3. During your most recent visit, did this doctor explain things in a way that was easy to understand?

1☐ Yes
2☐ No

RV4. During your most recent visit, did you talk with this doctor about any health problems or concerns?

1☐ Yes
2☐ No → **If No, go to question RV6**

RV5. During your most recent visit, did this doctor give you easy to understand instructions about what to do to take care of these health problems or concerns?

1☐ Yes
2☐ No

RV6. During your most recent visit, did this doctor seem to know the important information about your medical history?

1☐ Yes
2☐ No

RV7. During your most recent visit, did this doctor show concern about your health and how you were feeling?

[1]☐ Yes
[2]☐ No

RV8. During your most recent visit, did this doctor spend enough time with you?

[1]☐ Yes
[2]☐ No

RV9. During your most recent visit, did clerks and receptionists at this doctor's office treat you with courtesy and respect?

[1]☐ Yes
[2]☐ No

RV10. Using any number from 0 to 10, where 0 is the worst medical care possible and 10 is the best medical care possible, what number would you use to rate the medical care you received during your most recent visit with this doctor?

☐ 0 Worst medical care possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best medical care possible

RV11. Please tell us how this doctor's office could have improved the care and services you received at your most recent visit.

_____

Measure # 4b: Consumer Assessment of Healthcare Providers and Systems (CAHPS) – Adult Specialty Care 1.0

Contact Information:

- Contact the CAHPS Help Line at cahps1@ahrq.gov or 1-800-492-9261 with questions or comments about the content or implementation of CAHPS surveys, the use of CAHPS surveys for consumer reporting or quality improvement, events sponsored by the CAHPS User Network, or the usability of the CAHPS Web site.

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Additional Notes:

- To learn more about using the CAHPS "Clinician and Group Survey" instruments, visit: https://www.cahps.ahrq.gov/content/products/CG/PROD_CG_CG40Products.asp?p=1021&s=213.

CAHPS® Clinician & Group Survey

Version: Adult Specialty Care Questionnaire 1.0

Language: English

Response Scale: 4 points

Note regarding the Never-to-Always response scale: This questionnaire employs a four-point response scale – "Never/Sometimes/Usually/Always" – which is the standard scale for CAHPS surveys. An alternative six-point scale adds "Almost never" and "Almost always" to the response options. Questionnaires with the six-point scale are available for downloading at https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX6p.asp.

A version of the questionnaire with the six-point scale has been used by several early adopters of the survey; it is also the version that was endorsed by the National Quality Forum. The CAHPS Consortium is examining the performance of the two response scales in the context of this survey.

File name: 352a-4_AdultSpec_Eng_4pt_V1.doc
Last updated: October 6, 2008

Instructions for Front Cover

- Replace the cover of this document with your own front cover. Include a user-friendly title and your own logo.
- Include this text regarding the confidentiality of survey responses:

  Your Privacy is Protected. All information that would let someone identify you or your family will be kept private. {VENDOR NAME} will not share your personal information with anyone without your OK. Your responses to this survey are also completely **confidential**. You may notice a number on the cover of the survey. This number is used **only** to let us know if you returned your survey so we don't have to send you reminders.

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

  What To Do When You're Done. Once you complete the survey, place it in the envelope that was provided, seal the envelope, and return the envelope to [INSERT VENDOR ADDRESS].

  If you want to know more about this study, please call XXX-XXX-XXXX.

Instructions for Format of Questionnaire

Proper formatting of a questionnaire improves response rates, the ease of completion, and the accuracy of responses. The CAHPS team's recommendations include the following:

- If feasible, insert blank pages as needed so that the survey instructions (see next page) and the first page of questions start on the right-hand side of the questionnaire booklet.
- Maximize readability by using two columns, serif fonts for the questions, and ample white space.
- Number the pages of your document, but remove the headers and footers inserted to help sponsors and vendors distinguish among questionnaire versions.

Additional guidance is available in **Preparing a Questionnaire Using the CAHPS Clinician & Group Survey**:
https://www.cahps.ahrq.gov/cahpskit/files/32_CG_Preparing_a_Questionnaire.pdf

---

Survey Instructions

Answer each question by marking the box to the left of 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 on page 1**
☐ No

Your Doctor

1. Our records show that you got care from the doctor named below in the last 12 months.

Name of doctor label goes here

Is that right?

1☐ Yes
2☐ No → **If No, go to #26 on page 4**

The questions in this survey booklet will refer to the doctor named in Question 1 as "this doctor." Please think of that doctor as you answer the survey.

2. Is this the doctor you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?

1☐ Yes
2☐ No

3. How long have you been going to this doctor?

1☐ Less than 6 months
2☐ At least 6 months but less than 1 year
3☐ At least 1 year but less than 3 years
4☐ At least 3 years but less than 5 years
5☐ 5 years or more

Your Care From This Doctor in the Last 12 Months

These questions ask about **your own** health care. Do **not** include care you got when you stayed overnight in a hospital. Do **not** include the times you went for dental care visits.

4. In the last 12 months, how many times did you visit this doctor to get care for yourself?

1☐ None → **If None, go to #26 on page 4**
2☐ 1 time
3☐ 2
4☐ 3
5☐ 4
6☐ 5 to 9
7☐ 10 or more times

5. In the last 12 months, did you phone this doctor's office to get an appointment for an illness, injury or condition that **needed care right away**?

1☐ Yes
2☐ No → **If No, go to #7**

6. In the last 12 months, when you phoned this doctor's office to get an appointment for **care you needed right away**, how often did you get an appointment as soon as you thought you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

7. In the last 12 months, did you make any appointments for a **check-up or routine care** with this doctor?

1☐ Yes
2☐ No → **If No, go to #9**

8. In the last 12 months, when you made an appointment for a **check-up or routine care** with this doctor, how often did you get an appointment as soon as you thought you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

9. In the last 12 months, did you phone this doctor's office with a medical question during regular office hours?

1☐ Yes
2☐ No → **If No, go to #11**

10. In the last 12 months, when you phoned this doctor's office during regular office hours, how often did you get an answer to your medical question that same day?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

11. In the last 12 months, did you phone this doctor's office with a medical question **after** regular office hours?

1☐ Yes
2☐ No → **If No, go to #13**

12. In the last 12 months, when you phoned this doctor's office **after** regular office hours, how often did you get an answer to your medical question as soon as you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

13. Wait time includes time spent in the waiting room and exam room. In the last 12 months, how often did you see this doctor **within 15 minutes** of your appointment time?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

14. In the last 12 months, how often did this doctor explain things in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

15. In the last 12 months, how often did this doctor listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

16. In the last 12 months, did you talk with this doctor about any health problems or concerns?

1☐ Yes
2☐ No → **If No, go to #18**

17. In the last 12 months, how often did this doctor give you easy to understand instructions about taking care of these health problems or concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

18. In the last 12 months, how often did this doctor seem to know the important information about your medical history?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

19. In the last 12 months, how often did this doctor show respect for what you had to say?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

20. In the last 12 months, how often did this doctor spend enough time with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

21. In the last 12 months, did this doctor order a blood test, x-ray or other test for you?

1☐ Yes
2☐ No → **If No, go to #23**

22. In the last 12 months, when this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

23. Using any number from 0 to 10, where 0 is the worst doctor possible and 10 is the best doctor possible, what number would you use to rate this doctor?

☐ 0 Worst doctor possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best doctor possible

Clerks and Receptionists at This Doctor's Office

24. In the last 12 months, how often were clerks and receptionists at this doctor's office as helpful as you thought they should be?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

25. In the last 12 months, how often did clerks and receptionists at this doctor's office treat you with courtesy and respect?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

About You

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

1☐ Excellent
2☐ Very good
3☐ Good
4☐ Fair
5☐ Poor

27. A health provider is a doctor, nurse or anyone else you would see for health care. In the past 12 months, have you seen a doctor or other health provider 3 or more times for the same condition or problem?

1☐ Yes
2☐ No → **If No, go to #29**

28. Is this a condition or problem that has lasted for at least 3 months? Do **not** include pregnancy or menopause.

1☐ Yes
2☐ No

29. Do you now need or take medicine prescribed by a doctor? Do **not** include birth control.

1☐ Yes
2☐ No → **If No, go to # 31**

30. Is this medicine to treat a condition that has lasted for at least 3 months? Do **not** include pregnancy or menopause.

1☐ Yes
2☐ No

31. What is your age?

1☐ 18 to 24
2☐ 25 to 34
3☐ 35 to 44
4☐ 45 to 54
5☐ 55 to 64
6☐ 65 to 74
7☐ 75 or older

32. Are you male or female?

1☐ Male
2☐ Female

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

1☐ 8th grade or less
2☐ Some high school, but did not graduate
3☐ High school graduate or GED
4☐ Some college or 2-year degree
5☐ 4-year college graduate
6☐ More than 4-year college degree

34. Are you of Hispanic or Latino origin or descent?

1☐ Yes, Hispanic or Latino
2☐ No, not Hispanic or Latino

35. What is your race? Please mark one or more.

1☐ White
2☐ Black or African American
3☐ Asian
4☐ Native Hawaiian or Other Pacific Islander
5☐ American Indian or Alaskan Native
6☐ Other

36. Did someone help you complete this survey?

1☐ Yes
2☐ No → **Thank you.**
Please return the completed survey in the postage-paid envelope.

37. How did that person help you? Mark all that apply.

1☐ Read the questions to me
2☐ Wrote down the answers I gave
3☐ Answered the questions for me
4☐ Translated the questions into my language
5☐ Helped in some other way

Please print: _____

_____

_____

Thank you

Please return the completed survey in the postage-paid envelope.

CAHPS® Clinician & Group Survey

Supplemental Items for the Adult Specialty Care Questionnaire 1.0

Language: English

Response Scale: 4 points

File name: 352a-4_AdultSpec_Eng_4pt_V1.doc
Last updated: October 6, 2008

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Important instructions

Placing Supplemental Items in the Core Questionnaires. After you copy one or more supplemental items into the core questionnaire:

- **Fix the formatting** of the items as needed to fit into the two-column format.
- **Renumber** the supplemental item and **ALL** subsequent items so that they are consecutive.
- **Revise ALL skip instructions** in the questionnaire to make sure they point the respondent to the correct item number.

Care You Got From This Doctor

Insert DC1 – DC2 after core question 14.

DC1. In the last 12 months, how often did this doctor check to be sure you understood everything?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

DC2. In the last 12 months, how often did this doctor encourage you to ask questions?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert DC3 after core question 15.

DC3. In the last 12 months, how often did this doctor let you talk without interruptions?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert DC4 after core question 17.

DC4. In the last 12 months, did this doctor talk with you about specific things you could do to manage your condition?

1☐ Yes
2☐ No

Insert DC5 after core question 18.

DC5. How would you rate this doctor's knowledge of you as a person, including values and beliefs that are important to you?

1☐ Very poor
2☐ Poor
3☐ Fair
4☐ Good
5☐ Very good
6☐ Excellent

Insert DC6 – DC7 before core question 21.

DC6. In the last 12, months did this doctor ever examine you?

1☐ Yes
2☐ No → **If No, go to core question 21**

DC7. In the last 12 months, how often was this doctor as thorough as you thought you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Coordinating Your Care

Insert CC1 before core question 21.

CC1. In the last 12 months, did this doctor talk with you about all of the prescription medicines you were taking?

1☐ Yes
2☐ No

Cost of Care (Prescriptions)

Insert COC1 – COC2 after core question 20.

COC1. In the last 12 months, did you take any prescription medicine?

[1]☐ Yes
[2]☐ No → **If No, go to core question 21**

COC2. In the last 12 months, were you ever worried or concerned about the cost of your prescription medicine?

[1]☐ Yes
[2]☐ No

Doctor Role

Insert DR1 after core question 2.

DR1. Which of the following best describes this doctor's role in your care?

[1]☐ This doctor has had an ongoing role in my care
[2]☐ I have only seen this doctor one time (one-time consultation, procedure or treatment)
[3]☐ Other

Shared Decision Making

Insert SD1 – SD3 before core question 21.

SD1. Choices for treatment or health care can include choices about medicine, surgery, or other treatment. In the last 12 months, did this doctor tell you there was more than one choice for your treatment or health care?

[1]☐ Yes
[2]☐ No → **If No, go to core question 21**

SD2. In the last 12 months, did this doctor talk with you about the pros and cons of each choice for your treatment or health care?

[1]☐ Yes
[2]☐ No

SD3. In the last 12 months, when there was more than one choice for your treatment or health care, did this doctor ask which choice you thought was best for you?

1☐ Yes
2☐ No

Surgery or Procedures Done by This Doctor

Insert SP1 – SP6 after core question 22.

SP1. In the last 12 months, did this doctor perform surgery or a procedure on you?

1☐ Yes
2☐ No → **If No, go to core question 23**

SP2. In the last 12 months, did this doctor give you enough information on the surgery or procedure before it was done?

1☐ Definitely yes
2☐ Somewhat yes
3☐ Somewhat no
4☐ Definitely no

SP3. In the last 12 months, did this doctor make sure you had enough pain relief during the surgery or procedure?

1☐ Definitely yes
2☐ Somewhat yes
3☐ Somewhat no
4☐ Definitely no

SP4. In the last 12 months, did this doctor give you medications to relieve your pain after the procedure or surgery?

1☐ Yes
2☐ No

SP5. In the last 12 months, did you phone this doctor's office for help or advice after the procedure or surgery?

1☐ Yes
2☐ No → **If No, go to core question 23**

SP6. In the last 12 months, when you phoned this doctor's office for help or advice after the procedure or surgery, did you get the medical help or advice you needed?

1☐ Yes
2☐ No

Measure # 4c: Consumer Assessment of Healthcare Providers and Systems (CAHPS) – Child Primary Care 1.0

Contact Information:

- Contact the CAHPS Help Line at cahps1@ahrq.gov or 1-800-492-9261 with questions or comments about the content or implementation of CAHPS surveys, the use of CAHPS surveys for consumer reporting or quality improvement, events sponsored by the CAHPS User Network, or the usability of the CAHPS Web site.

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Additional Notes:

- To learn more about using the CAHPS "Clinician and Group Survey" instruments, visit: https://www.cahps.ahrq.gov/content/products/CG/PROD_CG_CG40Products.asp?p=1021&s=213.

CAHPS® Clinician & Group Survey

Version: Child Primary Care Questionnaire 1.0

(Note: A 2.0 version of this instrument is also available.)

Language: English

Response Scale: 4 points

Note regarding the Never-to-Always response scale: This questionnaire employs a four-point response scale – "Never/Sometimes/Usually/Always" – which is the standard scale for CAHPS surveys. An alternative six-point scale adds "Almost never" and "Almost always" to the response options. Questionnaires with the six-point scale are available for downloading at https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX6p.asp.

A version of the questionnaire with the six-point scale has been used by several early adopters of the survey; it is also the version that was endorsed by the National Quality Forum. The CAHPS Consortium is examining the performance of the two response scales in the context of this survey.

File name: 353a-4_ChildPrim_Eng_4pt_V1.doc
Last updated: October 7, 2008

Instructions for Front Cover

- Replace the cover of this document with your own front cover. Include a user-friendly title and your own logo.
- Include this text regarding the confidentiality of survey responses:

  Your Privacy is Protected. All information that would let someone identify you or your family will be kept private. {VENDOR NAME} will not share your personal information with anyone without your OK. Your responses to this survey are also completely **confidential**. You may notice a number on the cover of the survey. This number is used **only** to let us know if you returned your survey so we don't have to send you reminders.

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

  What To Do When You're Done. Once you complete the survey, place it in the envelope that was provided, seal the envelope, and return the envelope to [INSERT VENDOR ADDRESS].

  If you want to know more about this study, please call XXX-XXX-XXXX.

Instructions for Format of Questionnaire

Proper formatting of a questionnaire improves response rates, the ease of completion, and the accuracy of responses. The CAHPS team's recommendations include the following:

- If feasible, insert blank pages as needed so that the survey instructions (see next page) and the first page of questions start on the right-hand side of the questionnaire booklet.
- Maximize readability by using two columns, serif fonts for the questions, and ample white space.
- Number the pages of your document, but remove the headers and footers inserted to help sponsors and vendors distinguish among questionnaire versions.

Additional guidance is available in **Preparing a Questionnaire Using the CAHPS Clinician & Group Survey**:
https://www.cahps.ahrq.gov/cahpskit/files/32_CG_Preparing_a_Questionnaire.pdf

---

Survey Instructions

Answer each question by marking the box to the left of 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 on page 1**
☐ No

Please answer the questions for the child listed on the envelope. Please do not answer for any other children.

Your Child's Doctor

1. Our records show that your child got care from the doctor named below in the last 12 months.

Name of doctor label goes here

Is that right?

1☐ Yes
2☐ No → **If No, go to #26 on page 4**

The questions in this survey booklet will refer to the doctor named in Question 1 as "this doctor." Please think of that doctor as you answer the survey.

2. Is this the doctor you usually see if your child needs a check-up or gets sick or hurt?

1☐ Yes
2☐ No

3. How long has your child been going to this doctor?

1☐ Less than 6 months
2☐ At least 6 months but less than 1 year
3☐ At least 1 year but less than 3 years
4☐ At least 3 years but less than 5 years
5☐ 5 years or more

Your Child's Care From This Doctor in the Last 12 Months

These questions ask about **your child's** health care. Do **not** include care your child got when he or she stayed overnight in a hospital. Do **not** include the times your child went for dental care visits.

4. In the last 12 months, how many times did your child visit this doctor for care?

1☐ None → **If None, go to #26 on page 4**
2☐ 1 time
3☐ 2
4☐ 3
5☐ 4
6☐ 5 to 9
7☐ 10 or more times

5. In the last 12 months, did you phone this doctor's office to get an appointment for your child for an illness, injury or condition that **needed care right away**?

1☐ Yes
2☐ No → **If No, go to #7**

6. In the last 12 months, when you phoned this doctor's office to get an appointment for **care your child needed right away**, how often did you get an appointment as soon as you thought your child needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

7. In the last 12 months, did you make any appointments for a **check-up or routine care** for your child with this doctor?

1☐ Yes
2☐ No → **If No, go to #9**

8. In the last 12 months, when you made an appointment for a **check-up or routine care** for your child with this doctor, how often did you get an appointment as soon as you thought your child needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

9. In the last 12 months, did you phone this doctor's office with a medical question about your child during regular office hours?

1☐ Yes
2☐ No → **If No, go to #11**

10. In the last 12 months, when you phoned this doctor's office during regular office hours, how often did you get an answer to your medical question that same day?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

11. In the last 12 months, did you phone this doctor's office with a medical question about your child **after** regular office hours?

1☐ Yes
2☐ No → **If No, go to #13**

12. In the last 12 months, when you phoned this doctor's office **after** regular office hours, how often did you get an answer to your medical question as soon as you needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

13. Wait time includes time spent in the waiting room and exam room. In the last 12 months, how often did your child see this doctor **within 15 minutes** of his or her appointment time?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

14. In the last 12 months, how often did this doctor explain things about your child's health in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

15. In the last 12 months, how often did this doctor listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

16. In the last 12 months, did you talk with this doctor about any problems or concerns you had about your child's health?

1☐ Yes
2☐ No → **If No, go to #18**

17. In the last 12 months, how often did this doctor give you easy to understand instructions about taking care of these health problems or concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

18. In the last 12 months, how often did this doctor seem to know the important information about your child's medical history?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

19. In the last 12 months, how often did this doctor show respect for what you had to say?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

20. In the last 12 months, how often did this doctor spend enough time with your child?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

21. In the last 12 months, did this doctor order a blood test, x-ray or other test for your child?

1☐ Yes
2☐ No → **If No, go to #23**

22. In the last 12 months, when this doctor ordered a blood test, x-ray or other test for your child, how often did someone from this doctor's office follow up to give you those results?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

23. Using any number from 0 to 10, where 0 is the worst doctor possible and 10 is the best doctor possible, what number would you use to rate this doctor?

☐ 0 Worst doctor possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best doctor possible

Clerks and Receptionists at This Doctor's Office

24. In the last 12 months, how often were clerks and receptionists at this doctor's office as helpful as you thought they should be?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

25. In the last 12 months, how often did clerks and receptionists at this doctor's office treat you with courtesy and respect?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

About Your Child and You

26. In general, how would you rate your child's overall health?

1☐ Excellent
2☐ Very Good
3☐ Good
4☐ Fair
5☐ Poor

27. What is **your child's** age?

1☐ Less than 1 year old

_____ YEARS OLD *(write in)*

28. Is your child male or female?

1☐ Male
2☐ Female

29. Is your child of Hispanic or Latino origin or descent?

1☐ Yes, Hispanic or Latino
2☐ No, not Hispanic or Latino

30. What is your child's race? Please mark one or more.

1☐ White
2☐ Black or African-American
3☐ Asian
4☐ Native Hawaiian or other Pacific Islander
5☐ American Indian or Alaska Native
6☐ Other

31. What is **your** age?

- [0] ☐ Under 18
- [1] ☐ 18 to 24
- [2] ☐ 25 to 34
- [3] ☐ 35 to 44
- [4] ☐ 45 to 54
- [5] ☐ 55 to 64
- [6] ☐ 65 to 74
- [7] ☐ 75 or older

32. Are you male or female?

- [1] ☐ Male
- [2] ☐ Female

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

- [1] ☐ 8th grade or less
- [2] ☐ Some high school, but did not graduate
- [3] ☐ High school graduate or GED
- [4] ☐ Some college or 2-year degree
- [5] ☐ 4-year college graduate
- [6] ☐ More than 4-year college degree

34. How are you related to the child?

- [1] ☐ Mother or father
- [2] ☐ Grandparent
- [3] ☐ Aunt or uncle
- [4] ☐ Older brother or sister
- [5] ☐ Other relative
- [6] ☐ Legal guardian
- [7] ☐ Someone else

Please print: _____

_____

35. Did someone help you complete this survey?

- [1] ☐ Yes
- [2] ☐ No → **Thank you.**
  Please return the completed survey in the postage-paid envelope.

36. How did that person help you? Mark all that apply.

- [1] ☐ Read the questions to me
- [2] ☐ Wrote down the answers I gave
- [3] ☐ Answered the questions for me
- [4] ☐ Translated the questions into my language
- [5] ☐ Helped in some other way

Please print: _____

_____

_____

Thank you

Please return the completed survey in the postage-paid envelope.

CAHPS® Clinician & Group Survey

Supplemental Items for the Child Primary Care Questionnaire 1.0

(Note: A 2.0 version of this instrument is also available.)

Language: English

Response Scale: 4 points

File name: 353a-4_ChildPrim_Eng_4pt_V1.doc
Last updated: October 7, 2008

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Important instructions

Placing Supplemental Items in the Core Questionnaires. After you copy one or more supplemental items into the core questionnaire:

- **Fix the formatting** of the items as needed to fit into the two-column format.
- **Renumber** the supplemental item and **ALL** subsequent items so that they are consecutive.
- **Revise ALL skip instructions** in the questionnaire to make sure they point the respondent to the correct item number.

Definition of Specialist. If you choose to use one or more supplemental items that refer to specialists, please insert this definition before the first of these items: "Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care."

After Hours Care

Insert AH1 – AH2 after core question 12.

AH1. After hours care is health care when your child's usual doctor's office or clinic is closed. In the last 12 months, did you try to get any after hours care for your child at this doctor's office?

1☐ Yes
2☐ No → **If No, go to core question 13**

AH2. In the last 12 months, did the after hours care available from this doctor's office meet your needs?

1☐ Yes
2☐ No

Behavioral Health

Insert MH1 after core question 26.

MH1. In general, how would your rate your child's overall mental or emotional health?

1☐ Excellent
2☐ Very good
3☐ Good
4☐ Fair
5☐ Poor

Doctor Communication With Child

Insert DC1 – DC4 after core question 20.

DC1. Is your child able to talk with doctors about his or her health care?

1☐ Yes
2☐ No → **If No, go to core question 21**

DC2. In the last 12 months, how often did this doctor explain things in a way that was easy for **your child** to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

DC3. In the last 12 months, how often did this doctor encourage **your child** to ask questions?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

DC4. In the last 12 months, how often did this doctor listen carefully to **your child**?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Doctor Thoroughness

Insert DT1 – DT2 before core question 21.

DT1. In the last 12 months, did this doctor ever examine your child?

1☐ Yes
2☐ No → **If No, go to core question 21**

DT2. In the last 12 months, how often was this doctor as thorough as you thought your child needed?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Health Improvement

Insert HI1 after core question 17.

HI1. In the last 12 months, did you and this doctor talk about specific things you could do to prevent illness in your child?

[1]☐ Yes
[2]☐ No

Prescription Medicines

Insert PM1 after core question 20.

PM1. In the last 12 months, did this doctor talk with you about all of the prescription medicines your child was taking?

[1]☐ Yes
[2]☐ No

Provider Knowledge of Specialist Care

Insert PK1 – PK2 after core question 20. Note: These items are recommended for use only if the sampled provider is not a specialist.

PK1. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 12 months, did this doctor suggest your child see a specialist for a particular health problem?

[1]☐ Yes
[2]☐ No → **If No, go to core question 21**

PK2. In the last 12 months, how often did the doctor named in Question 1 seem informed and up-to-date about the care your child got from specialists?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

Shared Decision Making

Insert SD1 – SD4 before core question 21.

SD1. Choices for your child's treatment or health care can include choices about medicine, surgery, or other treatment. In the last 12 months, did this doctor tell you there was more than one choice for your child's treatment or health care?

1☐ Yes
2☐ No → **If No, go to core question 21**

SD2. In the last 12 months, did this doctor talk with you about the pros and cons of each choice for your child's treatment or health care?

1☐ Yes
2☐ No

SD3. In the last 12 months, did this doctor give you enough information about each choice?

1☐ Yes
2☐ No

SD4. In the last 12 months, when there was more than one choice for your child's treatment or health care, did this doctor ask which choice you thought was best for your child?

1☐ Yes
2☐ No

Measure # 5: Care Coordination Measurement Tool (CCMT)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:
Richard C. Antonelli, MD, MS
Medical Director for Integrated Care
Children's Hospital Boston Integrated Care Organization
319 Longwood Avenue
Boston, MA 02115
P: (617) 919-4269. F: (617) 919-3090
richard.antonelli@childrens.harvard.edu

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Medical Home Care Coordination Measurement Tool©

Site Code: ___ Form # ___ of ___

Date	Patient Study Code And Age	Patient Level	Focus	Care Coordination Needs	Activity Code(s)	Outcome(s) Prevented	Outcome(s) Occurred	Time Spent* 1	2	3	4	5	6	7	Staff	Clinical Comp.	Initials

Patient Level

Level	Description
I	Non-CSHCN, **Without** Complicating Family or Social Issues
II	Non-CSHCN, **With** Complicating Family or Social Issues
III	CSHCN, **Without** Complicating Family or Social Issues
IV	CSHCN, **With** Complicating Family or Social Issues

Focus of Encounter (choose **ONE)**

1. Mental Health
2. Developmental / Behavioral
3. Educational / School
4. Legal / Judicial
5. Growth / Nutrition
6. Referral Management
7. Clinical / Medical Management
8. Social Services (ie. housing, food, clothing, ins., trans.)

Rev-09/10

Care Coordination Needs
(choose **all that apply**)

1. Make Appointments
2. Follow-Up Referrals
3. Order Prescriptions, Supplies, Services, etc.
4. Reconcile Discrepancies
5. Coordination Services (schools, agencies, payers etc.)

Time Spent

1 – less than **5** minutes
2 – **5 to 9** minutes
3 – **10 to 19** minutes
4 – **20 to 29** minutes
5 – **30 to 39** minutes
6 – **40 to 49** minutes
7 – **50** minutes and greater*
(*Please NOTE **actual minutes** if greater than 50)

Staff

RN, LPN, MD, NP, PA, MA, SW, Cler

Clinical Competence

C= Clinical Competence required
NC= Clinical Competence not Required

Activity to Fulfill Needs
(choose **all that apply**)

1. **Telephone discussion with:**
   a. Patient
   b. Parent/family
   c. School
   d. Agency
   e. Hospital/Clinic
   f. Payer
   g. Voc. / training
   h. Pharmacy
2. **Electronic (E-Mail) Contact with:**
   a. Patient
   b. Parent
   c. School
   d. Agency
   e. Hospital/Clinic
   f. Payer
   g. Voc. / training
   h. Pharmacy
3. **Contact with Consultant**
   a. Telephone
   b. Meeting
   c. Letter
   d. E-Mail
4. **Form Processing**: (eg. school, camp, or complex record release)
5. **Confer with Primary Care Physician**
6. **Written Report to Agency**: (eg. SSI)
7. **Written Communication**
   a. E-Mail
   b. Letter
8. **Chart Review**
9. **Patient-focused Research**
10. **Contact with Home Care Personnel**
    a. Telephone
    b. Meeting
    c. Letter
    d. E-Mail
11. **Develop / Modify Written Care Plan**
12. **Meeting/Case Conference**

Outcome(s)

As a result of this care coordination activity, the following was **PREVENTED** (choose **ONLY ONE**, if applicable):

1a. ER visit
1b. Subspecialist visit
1c. Hospitalization
1d. Visit to Pediatric Office/Clinic
1e. Lab / X-ray
1f. Specialized Therapies (PT, OT, etc)

2. As a result of this care coordination activity, the following **OCCURRED** (choose **all that apply**):

2a. Advised family/patient on home management
2b. Referral to ER
2c. Referral to subspecialist
2d. Referral for hospitalization
2e. Referral for pediatric sick office visit
2f. Referral to lab / X-ray
2g. Referral to community agency
2h. Referral to Specialized Therapies
2i. Ordered prescription, equipment, diapers, taxi, etc.
2j. Reconciled discrepancies (including missing data, miscommunications, compliance issues)
2k. Reviewed labs, specialist reports, IEP's, etc.
2l. Advocacy for family/patient
2m. Met family's immediate needs, questions, concerns
2n. Unmet needs (**PLEASE SPECIFY**)
2o. Not Applicable / Don't Know
2p. Outcome Pending

R. Antonelli, MD, FAAP

Supported by grant HRSA-02-MCHB-25A-AB

Courtesy of Children's Hospital Boston

Children's Hospital Boston

Measure # 6: Client Perception of Coordination Questionnaire (CPCQ)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:
  Clare F. McGuiness, PhD.
  Clare.mcguiness@ipnet.com.au

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Client Perception of Coordination Questionnaire (CPCQ)

1. How often did you get the services you thought you needed?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

2. How often did you have to wait too long to obtain a service/appointment?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

3. How often was it difficult to get transport to services?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

4. In the past 3 months, how often did you seem to receive the medicines you thought you needed?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always ☐ Not Applicable

5. How often did providers seem to be unnecessarily repeating tests or assessments?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always ☐ Not Applicable

6. How often were results of tests or assessments discussed with you, e.g. blood tests?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always ☐ Not Applicable

7. In the past 3 months, how often did you feel the care you received was well coordinated?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

8. How often were you happy with the quality of care you received?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

9. How often were you confused about the roles of different service providers?

   ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

10. In the past 3 months, how often have service providers responded appropriately to changes in your needs?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always ☐ Not Applicable

11. How often did you seem to get conflicting advice from service providers?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

12. In the past 3 months, how often have you felt like complaining about any of your care?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

13. How often did you feel you understood your conditions?

☐ Not at all Well ☐ Fairly Well ☐ Very Well

14. How often did you feel you could cope with life?

☐ Not at all Well ☐ Fairly Well ☐ Very Well

15. Overall, how satisfied are you with the care you have received in the past 3 months?

☐ Very Dissatisfied ☐ Moderately Dissatisfied ☐ Neutral ☐ Moderately Satisfied ☐ Very Satisfied

Questions **16 to 19** relate to the care you have received from your **General Practitioner** in the past 3 months.

16. How often did you and your GP **agree** about your care needs?

☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

17. How often did your GP seem to be **communicating** with your other providers?

☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

18. How often did your GP **involve you** when making decisions about your care?

☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

19. How often does your GP talk with you about your **future care**?

☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

20. How important is it to you to **be involved in decisions** with your GP about your care?

☐ Not at all Important ☐ Somewhat Important ☐ Very Important

21. Do you currently have a "Case Manager"? (A Case Manager is a type of service provider.)

Yes. ☐ Go to 24

No. ☐ Go to next question

22. Is your GP the **only** service provider you have seen in the past three months?

Yes. ☐ Go to question 29

No. ☐ Go to next question

23. Nominate **one service provider,** other than your GP, whom you have seen in the past three months.

☐ Specialist
☐ Nurse
☐ Home and Community Care
☐ Social Worker
☐ Other Specify: _____

Questions 24 to 28 relate to the care you have received from your case manager or the service provider that you have just nominated, in the past 3 months.

24. How often did you and that service provider agree about your care needs?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

25. How often did that service provider seem to be communicating with your other providers?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

26. How often did that service provider involve you when making decisions about your care?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

27. How often does that service provider talk with you about your future care?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

28. How important is it to you to be involved in decisions with that service provider about your care?

    ☐ Not at all Important ☐ Somewhat Important ☐ Very Important

Questions 29 to 31 relate to carers. By 'carer' we mean someone **you rely on to help with daily life,** but is not paid to do so – ie, a friend or relative.

29. Who are your carers?

    ☐ No carer
    ☐ Spouse
    ☐ Parent
    ☐ Daughter
    ☐ Son
    ☐ Other relative
    ☐ Friend
    ☐ Neighbour
    ☐ Other Specify: _____

30. In the past 3 months, how often was your **main carer** involved in making decisions about your care?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

31. In the past 3 months, how often do you think your **main carer** was satisfied with the care you received?

    ☐ Never ☐ Rarely ☐ Sometimes ☐ Mostly ☐ Always

Measure # 7a: Collaborative Practice Set (CPS) – Nurse Scale

Contact Information:

- Contact information unavailable.

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Measure # 7b Collaborative Practice Set (CPS) – Physician Scale

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- Contact information unavailable.

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Measure # 8: Breast Cancer Patient and Practice Management Process Measures

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- Contact information unavailable.

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Measure # 9a: Care Transitions Measure (CTM-3)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Eric A. Coleman, MD, MPH:
Director, Care Transitions Program
13199 East Montview Blvd, Suite 400
Aurora, Colorado 80045
P: (303) 724-2456. F: (303) 724-2486
Eric.Coleman@ucdenver.edu
www.caretransitions.org

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CARE TRANSITIONS MEASURE (CTM-3)

Patient Name: _____ Date: _____

1. The hospital staff took my preferences and those of my family or caregiver into account in deciding ***what*** my health care needs would be when I left the hospital.

Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Don't Know/ Don't Remember/ Not Applicable**

2. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.

Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Don't Know/ Don't Remember/ Not Applicable**

3. When I left the hospital, I clearly understood the purpose for taking each of my medications.

Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Don't Know/ Don't Remember/ Not Applicable**

Care Transitions Program; Denver, Colorado
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Measure # 9b: Care Transitions Measure (CTM-15)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Eric A. Coleman, MD, MPH:
Director, Care Transitions Program
13199 East Montview Blvd, Suite 400
Aurora, Colorado 80045
P: (303) 724-2456. F: (303) 724-2486
Eric.Coleman@ucdenver.edu
www.caretransitions.org

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CARE TRANSITIONS MEASURE (CTM-15)

Patient Name: _____ Date: _____

Who completed interview? θ Patient θ Caregiver

The first few statements are about the time you were in the hospital . . .

1. Before I left the hospital, the staff and I agreed about clear health goals for me and how these would be reached.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

2. The hospital staff took my preferences and those of my family or caregiver into account in deciding ***what*** my health care needs would be when I left the hospital.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

3. The hospital staff took my preferences and those of my family or caregiver into account in deciding ***where*** my health care needs would be met when I left the hospital.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

The next set of statements is about when you were preparing to leave the hospital . . .

4. When I left the hospital, I had all the information I needed to be able to take care of myself.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

5. When I left the hospital, I clearly understood how to manage my health.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

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6. When I left the hospital, I clearly understood the warning signs and symptoms I should watch for to monitor my health condition.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

7. When I left the hospital, I had a readable and easily understood written plan that described how all of my health care needs were going to be met.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

8. When I left the hospital, I had a good understanding of my health condition and what makes it better or worse.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

9. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

10. When I left the hospital, I was confident that I knew what to do to manage my health.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

11. When I left the hospital, I was confident I could actually do the things I needed to do to take care of my health.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

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The next statement is about your follow-up doctors' appointments . . .

12. When I left the hospital, I had a readable and easily understood written list of the appointments or tests I needed to complete within the next several weeks.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

The next set of statements is about your medications…

13. When I left the hospital, I clearly understood the ***purpose*** for taking each of my medications.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

14. When I left the hospital, I clearly understood ***how*** to take each of my medications, including how much I should take and when.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

15. When I left the hospital, I clearly understood the possible ***side effects*** of each of my medications.

Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

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Measure # 10: Patient Assessment of Care for Chronic Conditions (PACIC)

Contact Information:

- Contact information unavailable.

Russell E. Glasgow, Ph.D.
Deputy Director for Dissemination and Implementation Science
Division of Cancer Control and Population Sciences
National Cancer Institute (NCI)
6130 Executive Blvd., Room 6144
Rockville, MD 20852
P: (301) 435-4912; F: (301) 594-6787
russg@re-aim.net

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Measure # 11a: Family-Centered Care Self-Assessment Tool – Family Version

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Measure # 11b: Family-Centered Care Self-Assessment Tool – Provider Version

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Measure # 12a: ICU Nurse-Physician Questionnaire – Long Versions

Contact Information:

- For questions regarding this measure and for permission to use it, contact either:

Stephen M. Shortell
Dean and Professor
School of Public Health
University of California, Berkeley
50 University Hall #7360
Berkeley, CA 94720-7360, USA
shortell@berkeley.edu

or:

Dr. Denise M. Rousseau
University Professor
Carnegie Mellon University
H.J. Heinz II Professor of Organizational Behavior and Public Policy
Heinz College and Tepper School of Business
P: (412) 268-8470
rousseau@andrew.cmu.edu

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

School of Public Health
University of California, Berkeley

Principal Investigator: **Stephen M. Shortell, Ph. D.**

Senior Investigators: **Denise M. Rousseau, Ph. D.**
Edward F. X. Hughes, M.D., M.P.H.

Project Director: **Robin R. Gillies, Ph. D.**

ICU Nurse Questionnaire
(Long version)

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS
NATIONAL STUDY BACKGROUND INFORMATION

Overall Purpose

The questionnaire you are being asked to complete is part of a nation-wide study of the organization, management, and performance of intensive care units. The purpose of this study is to examine the organization and management practices of ICUs and their relationship to patient severity adjusted outcomes. A long term goal is to develop managerial and organizational guidelines which you and other hospitals can use to improve the quality of ICU care and reduce mortality. It is estimated that such improvements could save up to 10,000 lives a year.

Questionnaire Content

The questionnaires you have been given have been used successfully in many other organizational studies and have been extensively pre-tested. The questions are concerned with issues related to communication, coordination, conflict management, leadership, perceived unit team effectiveness, organizational culture, and related factors. Please keep in mind that questions pertaining to physicians refer to full and part-time salaried ICU physicians, house staff, and attending physicians who regularly admit to the ICU. We estimate that the questionnaire will take approximately 45 minutes to complete.

How You Benefit

Completion of these questions will be of direct benefit to you in two ways. First, we will provide you with specific feedback (in aggregate) on your unit's score on each of the measures of interest. Second, we will provide you with a comparison of your unit's score with that of the other hospitals in the study. This will enable you to assess your comparative performance. The feedback on your unit's scores and the comparison with other hospitals can be used to assess your performance and serve as a basis for continuous improvement of the quality of care provided in your unit.

Please Keep in Mind

You are asked to respond to each question as you believe the situation really exists, not as you think it should be or wish it to be. Responses are confidential; the numbers on the questionnaires are for tracking returns. Analyses will be based on aggregate responses only.

Please seal the completed questionnaire in the envelope provided and place it in the U.S. Post Office mail. Thank you for your assistance.

Please note: ANY QUESTIONS WHICH YOU HAVE OR ASSISTANCE NEEDED IN COMPLETING THIS QUESTIONNAIRE SHOULD BE DIRECTED TO ANY ONE OF THE FOLLOWING INDIVIDUALS.

Robin Gillies, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(312) 491-5540~~ *(No longer valid)*

Denise Rousseau, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(312) 491-8073, 491-3470~~ *(No longer valid)*

Stephen M. Shortell, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(312) 491-5540~~ *(No longer valid)*

SECTION ONE: RELATIONSHIPS AND COMMUNICATIONS WITHIN THE ICU

I. For each of the following statements, please circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
Nurse-to-Nurse Relationships: These statements refer to relationships between nurses.					
1. I look forward to working with the nurses of this ICU each day.	1	2	3	4	5
2. It is easy for me to talk openly with the nurses of this ICU.	1	2	3	4	5
3. I can think of a number of times when I received incorrect information from nurses in this unit.	1	2	3	4	5
4. There is effective communication between nurses across shifts.	1	2	3	4	5
5. Communication between nurses in this unit is very open.	1	2	3	4	5
6. It is often necessary for me to go back and check the accuracy of information I have received from nurses in this unit.	1	2	3	4	5
7. I find it enjoyable to talk with other nurses of this unit.	1	2	3	4	5
8. Nurses in the unit are well informed regarding events occuring on other shifts.	1	2	3	4	5
9. When nurses talk with each other in this unit, there is a good deal of understanding.	1	2	3	4	5
10. The accuracy of information passed among nurses of this unit leaves much to be desired.	1	2	3	4	5
11. It is easy to ask advice from nurses in this unit.	1	2	3	4	5
12. I feel that certain ICU nurses don't completely understand the information they receive.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
					(1:19)
Nurse-to-Physician Relationships: These statements refer to relationships between nurses and physicians.					
13. I look forward to working with the physicians of this ICU each day.	1	2	3	4	5
14. It is easy for me to talk openly with the physicians of this ICU.	1	2	3	4	5
15. I can think of a number of times when I received incorrect information from physicians in this unit.	1	2	3	4	5
16. There is effective communication between nurses and physicians across shifts.	1	2	3	4	5
17. Communication between nurses and physicians in this unit is very open.	1	2	3	4	5
18. It is often necessary for me to go back and check the accuracy of information I have received from physicians in this unit.	1	2	3	4	5
19. I find it enjoyable to talk with physicians of this unit.	1	2	3	4	5
20. Physicians associated with the unit are well informed regarding events occuring on other shifts.	1	2	3	4	5
21. When nurses talk with physicians in this unit, there is a good deal of understanding.	1	2	3	4	5
22. The accuracy of information passed between nurses and physicians of this unit leaves much to be desired.	1	2	3	4	5
23. It is easy to ask advice from physicians in this unit.	1	2	3	4	5
24. I feel that certain ICU physicians don't completely understand the information they receive.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
					(1:31)
General Relationships and Communications: These statements refer to general relationships and communications within the ICU.					
25. I get information on the status of patients when I need it.	1	2	3	4	5
26. This ICU has goals and objectives different from my own.	1	2	3	4	5
27. Physicians are readily available for consultation.	1	2	3	4	5
28. When a patient's status changes, I get relevant information quickly.	1	2	3	4	5
29. I take pride in being associated with this ICU.	1	2	3	4	5
30. Nurses have a good understanding of physician goals.	1	2	3	4	5
31. There are needless delays in relaying information regarding patient care.	1	2	3	4	5
32. I identify with the goals and objectives of this ICU.	1	2	3	4	5
33. Physicians have a good understanding of nursing objectives.	1	2	3	4	5
34. I feel I am part of this ICU team.	1	2	3	4	5
35. In matters pertaining to patient care, nurses call physicians in a timely manner.	1	2	3	4	5
36. Nurses have a good understanding of physicians' treatment plans.	1	2	3	4	5
37. If I had a chance to do the same kind of work for the same pay in another unit of this hospital, I wouldn't go.	1	2	3	4	5
38. Nursing care plans are well understood by physicians in this unit.	1	2	3	4	5

39. Overall, how satisfied are you with the communications in this ICU? Circle the appropriate response.

	Very Dissatisfied 1	Dissatisfied 2	Neither Dissatisfied Nor Satisfied 3	Satisfied 4	Very Satisfied 5
					(1:45)
(a) nurse-to-nurse	1	2	3	4	5
b) physician-to-physician	1	2	3	4	5
(c) between nurses and physicians	1	2	3	4	5
(d) between patients and ICU nurses	1	2	3	4	5
(e) between patients and ICU physicians	1	2	3	4	5
(f) between patients' families and ICU nurses	1	2	3	4	5
(g) between patients' families and ICU physicians	1	2	3	4	5

40. How much say or influence do each of the following have over what goes on in this ICU? Circle the appropriate response. Circle "NA" if not applicable.

	No Influence At All (1)	Little Influence (2)	Moderate Influence (3)	Great Influence (4)	Very Great Influence (5)	NA (8)
						(1:52)
Hospital Administrators	(1)	(2)	(3)	(4)	(5)	(8)
Staff Nurses	(l)	(2)	(3)	(4)	(5)	(8)
Charge Nurses	(l)	(2)	(3)	(4)	(5)	(8)
Nurse Clinicians	(l)	(2)	(3)	(4)	(5)	(8)
Clinical Coordinators	(1)	(2)	(3)	(4)	(5)	(8)
Assistant Nurse Manager	(l)	(2)	(3)	(4)	(5)	(8)
Nurse Manager/Head Nurse	(l)	(2)	(3)	(4)	(5)	(8)
Medical Director	(l)	(2)	(3)	(4)	(5)	(8)
House Physicians	(l)	(2)	(3)	(4)	(5)	(8)
Residents/Interns	(l)	(2)	(3)	(4)	(5)	(8)
Private Attending Physicians Private Admitters	(l)	(2)	(3)	(4)	(5)	(8)

SECTION TWO: THE WORKPLACE AND FACILITIES*

II. This section focuses on your ICU facility, the equipment and supplies you work with, and the procedures you use on your job.

Listed on the next two pages are sets of words which could be used to describe one's workplace, equipment, supplies, and procedures.

For each set of words, circle the box between them that best describes your situation at work. For example, if you think your workplace is clean some of the time, but not all of the time, you would circle...

Section Two items (34 items) have been deleted. These items are property of Human Synergistics. Please contact Human Synergistics for more information on items and/or their use.

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SECTION THREE: THE ICU CULTURE*

III. Please think about what it takes for you and people like yourself (e.g. your co-workers, people in similar positions) to "fit in" and meet expectations in this ICU. Using the following response options, please indicate the extent to which people are expected to:

Not At All 1	To A Slight Extent 2	To A Moderate Extent 3	To A Great Extent 4	To A Very Great Extent 5

(1:97)

Section Three items (48 items) have been deleted. These items are property of Human Synergistics. Please contact Human Synergistics for more information on items and/or their use.

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SECTION FOUR: TEAMWORK AND LEADERSHIP

IV. For each of the following statements, circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

(2:25)

Nursing Leadership: These statements refer to your overall judgment of the characteristics of the ICU nursing leadership (i.e., nurse manager, assistant nurse manager, clinical nurse specialist, charge nurse; this excludes hospital administration). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

1. ICU nursing leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
2. ICU nursing leadership provides strong technical guidance and advice to nurses in the unit.	1	2	3	4	5
3. ICU nursing leadership invites staff participation but usually makes decisions itself.	1	2	3	4	5
4. ICU nursing leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
5. To the extent possible, ICU nursing leadership delegates to individual nurses the opportunity to solve their own patient care problems.	1	2	3	4	5
6. The ICU nursing leadership fails to make clear what they expect from members.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
					(2:31)
7. Unit nurses look to ICU nursing leadership to help solve technical patient care problems.	1	2	3	4	5
8. ICU nursing leadership actively directs group meetings designed to achieve unit objectives.	1	2	3	4	5
9. ICU nursing leadership discourages nurses from taking initiative.	1	2	3	4	5
10. Nurses in the unit are able to influence the thinking and behavior of ICU nursing leadership as much as ICU nursing leadership influences the thinking and behavior of unit nurses.	1	2	3	4	5
11. Unit nurses are uncertain where they stand with the ICU nursing leadership.	1	2	3	4	5
12. ICU nursing leadership is primarily provided through technical skill and knowledge.	1	2	3	4	5
13. ICU nursing leadership shares but does not give up control over the decision-making process.	1	2	3	4	5
14. The ICU nursing leadership is out of touch with nurse perceptions and concerns.	1	2	3	4	5
15. ICU nursing leadership is primarily exerted by making sure that the unit arrives at correct decisions.	1	2	3	4	5
16. ICU nursing leadership is primarily characterized by encouraging people to solve their own problems.	1	2	3	4	5
17. ICU nursing leadership often makes decisions without input from unit nurses.	1	2	3	4	5
18. In this ICU, nursing leadership is primarily exerted through preventing and correcting technical mistakes.	1	2	3	4	5
19. In this ICU, nursing leadership is primarily evidenced by giving staff opportunities for self-development.	1	2	3	4	5
20. ICU nursing leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

(2:45)

Physician Leadership: These statements refer to your overall judgment of the characteristics of the ICU physician leadership (i.e., ICU medical director and designated assistants or whichever physician is in charge of patient care). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

21. ICU physician leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
22. ICU physician leadership provides strong technical guidance and advice to nurses in the unit.	1	2	3	4	5
23. ICU physician leadership invites staff participation but usually makes decisions itself.	1	2	3	4	5
24. ICU physician leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
25. To the extent possible, ICU physician leadership delegates to individual unit members the opportunity to solve their own patient care problems.	1	2	3	4	5
26. The ICU physician leadership fails to make clear what they expect from members.	1	2	3	4	5
27. Unit nurses look to ICU physician leadership to help solve technical patient care problems.	1	2	3	4	5
28. ICU physician leadership actively directs group meetings designed to achieve unit objectives.	1	2	3	4	5
29. ICU physician leadership discourages nurses from taking initiative.	1	2	3	4	5
30. Nurses in the unit are able to influence the thinking and behavior of ICU physician leadership as much as ICU physician leadership influences the thinking and behavior of unit nurses.	1	2	3	4	5
31. Unit nurses are uncertain where they stand with the ICU physician leadership.	1	2	3	4	5
32. ICU physician leadership is primarily provided through technical skill and knowledge.	1	2	3	4	5
33. ICU physician leadership shares but does not give up control over the decision-making process.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

(2:58)

34. The ICU physician leadership is out of touch with nurse perceptions and concerns.	1	2	3	4	5
35. ICU physician leadership is primarily exerted by making sure that the unit arrives at correct decisions.	1	2	3	4	5
36. ICU physician leadership is primarily characterized by encouraging people to solve their own problems.	1	2	3	4	5
37. ICU physician leadership often makes decisions without input from unit nurses.	1	2	3	4	5
38. In this ICU, physician leadership is primarily exerted through preventing and correcting technical mistakes.	1	2	3	4	5
39. In this ICU, physician leadership is primarily evidenced by giving staff opportunities for self-development.	1	2	3	4	5
40. ICU physician leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

General: These statements refer in general to teamwork and leadership in the ICU.

41. We rarely achieve much progress in unit meetings.	1	2	3	4	5
42. Our unit has constructive work relationships with other groups in this hospital.	1	2	3	4	5
43. Unit meetings seem to be disorganized.	1	2	3	4	5
44. Our unit does not receive the cooperation it needs from other hospital units.	1	2	3	4	5
45. Our meetings address and resolve the issues that should be dealt with.	1	2	3	4	5
46. Other hospital subunits seem to have a low opinion of us.	1	2	3	4	5
47. ICU interests are adequately represented at higher levels of the hospital.	1	2	3	4	5
48. Inadequate working relationships with other hospital groups limit our effectiveness.	1	2	3	4	5

SECTION FIVE: PERCEIVED EFFECTIVENESS

V. For each of the following statements, circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
					(2:73)
1. Our unit almost always meets its patient care treatment goals.	1	2	3	4	5
2. Given the severity of the patients we treat, our unit's patients experience very good outcomes.	1	2	3	4	5
3. Our unit does a good job of meeting family member needs.	1	2	3	4	5
4. Our unit does a good job of applying the most recently available technology to patient care needs.	1	2	3	4	5
5. We are able to recruit the best ICU nurses.	1	2	3	4	5
6. We do a good job of retaining ICU nurses in the unit.	1	2	3	4	5
7. We are able to recruit the best ICU physicians.	1	2	3	4	5
8. We do a good job of retaining ICU physicians in the unit.	1	2	3	4	5
9. Overall, our unit functions very well together as a team.	1	2	3	4	5
10. Our unit is very good at responding to emergency situations.	1	2	3	4	5

11. Relative to other ICUs within your area, how does your unit compare on the following items?

	Much Worse Than 1	Somewhat Worse Than 2	Same As 3	Somewhat Better Than 4	Much Better Than 5
					(2:83)
a. Meeting its patient care treatment goals.	1	2	3	4	5
b. Patient care outcomes, taking into account patient severity	1	2	3	4	5
c. Meeting family member needs.	1	2	3	4	5
d. Applying the most recently available technology to patient care needs.	1	2	3	4	5
e. Recruiting ICU nurses.	1	2	3	4	5
f. Retaining ICU nurses.	1	2	3	4	5
g. Recruiting ICU physicians.	1	2	3	4	5
h. Retaining ICU physicians.	1	2	3	4	5

SECTION SIX--PART A: MANAGING DISAGREEMENTS BETWEEN NURSES

VI--PART A: Consider what happens when there is a disagreement or conflict between ICU nurses. Based on your experience in this unit, how likely is it that:

Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost Certain 5
					(2:91)
1. One nurse will force others to yield to his or her position.	1	2	3	4	5
2. Each nurse involved will give in a bit and settle on a compromise.	1	2	3	4	5
3. When nurses disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
4. When two nurses disagree, they will involve their superiors in resolving the issue.	1	2	3	4	5
5. Nurses will withdraw from the conflict.	1	2	3	4	5
6. All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
7. A superior will have to resolve the dispute between nurses.	1	2	3	4	5
8. All the nurses will work hard to arrive at the best possible solution.	1	2	3	4	5
9. A nurse will try hard to win by pressing his or her position.	1	2	3	4	5
10. The nurses involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
11. A problem between nurses will be referred to someone higher up.	1	2	3	4	5
12. Both parties will bargain away some of their desires in order to satisfy each other.	1	2	3	4	5
13. Nurses on both sides will agree to a less than optimal solution.	1	2	3	4	5
14. The nurses involved will take a firm position.	1	2	3	4	5
15. Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
16. Disagreements between nurses will be ignored.	1	2	3	4	5

SECTION SIX--PART B: MANAGING DISAGREEMENTS BETWEEN NURSES AND PHYSICIANS

VI--PART B: Consider what happens when there is a disagreement or conflict between ICU nurses and physicians. Based on your experience in this unit, how likely is it that:

Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost Certain 5
					(2:107)
1. One will force others to yield to his or her position.	1	2	3	4	5
2. Nurses and physicians involved will give in a bit and settle on a compromise.	1	2	3	4	5
3. When nurses and physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
4. When nurses and physicians disagree, they will involve their superiors in resolving the issue.	1	2	3	4	5
5. Both parties will withdraw from the conflict.	1	2	3	4	5
6. All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
7. A superior will have to resolve the dispute between nurses and physicians.	1	2	3	4	5
8. The nurses and physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
9. Each will try hard to win by pressing his or her position.	1	2	3	4	5
10. Both parties involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
11. A problem between nurses and physicians will be referred to someone higher up.	1	2	3	4	5
12. Both parties will bargain away some of their desires in order to satisfy each other.	1	2	3	4	5
13. Nurses and physicians will agree to a less than optimal solution.	1	2	3	4	5
14. Both parties involved will take a firm position.	1	2	3	4	5
15. Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
16. Disagreements between nurses and physicians will be ignored.	1	2	3	4	5

SECTION SEVEN: COORDINATION MECHANISMS

WITHIN THE ICU

VII--PART A: Various strategies and procedures can be used to coordinate patient care activities within an ICU. In your ICU, to what extent do each of the mechanisms listed below effectively contribute to the coordination of staff activities and the quality of patient care? Circle the appropriate response below. Please circle "8" if your ICU does not use the mechanism.

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Very Effective 4	Applicable Effective 5	Not (Not Used Here) 8
(3:7)						
a. Written rules, policies, and procedures?	1	2	3	4	5	8
b. Written plans and schedules?	1	2	3	4	5	8
c. Computerized information systems?	1	2	3	4	5	8
d. Unit directors' efforts to coordinate member activities?	1	2	3	4	5	8
e. One-to-one communication between staff?	1	2	3	4	5	8
f. Ad hoc group meetings?	1	2	3	4	5	8
g. Task forces and standing committees?	1	2	3	4	5	8
h. Written treatment protocols?	1	2	3	4	5	8
i. Daily staff rounds?	1	2	3	4	5	8

BETWEEN THE ICU AND OTHER HOSPITAL UNITS

VII--PART B: Various strategies and procedures can also be used to coordinate patient care activities between your ICU and other hospital units(e.g., operating room, emergency room, general medical/surgical floors, lab, respiratory therapy, etc.). In your ICU, to what extent do each of the mechanisms listed below effectively contribute to the coordination of your unit's activities with other hospital units? Circle the appropriate response below. Please circle "8" if your ICU does not use the mechanism.

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Very Effective 4	Applicable Effective 5	Not (Not Used Here) 8
(3:16)						
a. Written treatment protocols?	1	2	3	4	5	8
b. Ad hoc group meetings between ICU members and members of other units?	1	2	3	4	5	8

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Very Effective 4	Applicable Effective 5	Not (Not Used Here) 8
(3:18)						
c. Unit directors' personal efforts to coordinate activities between ICU staff and members of other units?	1	2	3	4	5	8
d. Written rules, policies, and procedures?	1	2	3	4	5	8
e. Written plans and schedules?	1	2	3	4	5	8
f. One-to-one communication between ICU staff and members of other units?	1	2	3	4	5	8
g. Task forces and standing committees involving members of the ICU and other units?	1	2	3	4	5	8
h. Daily staff rounds in which information is shared which helps assure coordination between other units and the ICU?	1	2	3	4	5	8
i. Computerized information systems?	1	2	3	4	5	8

SECTION EIGHT: AUTHORITY

VIII. For each of the following statements, circle the number on the scale which best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Agree Nor Disagree 3	Agree 4	Strongly Agree 5
(3:25)					
A. Our ICU Medical Director has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing physician staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Agree Nor Disagree 3	Strongly Agree 4	Agree 5
					(3:30)
B. The ICU Medical Director does a good job of involving members in:					
(l) Determining standards for patient care	1	2	3	4	5
(2) Determining staffing requirements	1	2	3	4	5
(3) Developing quality assurance programs	1	2	3	4	5
(4) Assuring that standards are met and corrective actions taken	1	2	3	4	5
(5) Researching, testing, and implementing changes	1	2	3	4	5
(6) Determining nursing staff patterns (e.g. primary/team/functional)	1	2	3	4	5
(7) Developing budgets based on staff objectives	1	2	3	4	5
C. Our ICU Nurse Manager/Head Nurse has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5
D. Our ICU Nurse Manager/Head Nurse does a good job of involving members in:					
(l) Determining standards for patient care	1	2	3	4	5
(2) Determining staffing requirements	1	2	3	4	5
(3) Developing quality assurance programs	1	2	3	4	5
(4) Assuring that standards are met and corrective actions taken	1	2	3	4	5
(5) Researching, testing, and implementing changes	1	2	3	4	5
(6) Determining nursing staff patterns (e.g. primary/team/functional)	1	2	3	4	5
(7) Developing budgets based on staff objectives	1	2	3	4	5

SECTION NINE: SATISFACTION

IX. Overall, how satisfied are you in your job? Check the appropriate face.

(3:49)

SECTION TEN: BACKGROUND INFORMATION

1a. Is your assignment in the ICU? (Circle one only)

1. ____permanent (hospital-employed) (3:50)
2. ____temporary (hospital-employed)
3. ____floating (hospital-employed)
4. ____per diem (hospital-employed)
5. ____contract (pre-specified duration)

If contract, length of contract _____months _____weeks _____days (3:51-6)

6. ____agency (day-by-day)

If agency, how many days have you worked in this unit during the past year? _____ (3:57-9)

1b. Is your assignment in the ICU?

1. ____full time 2. ____part time (3:60)

2. Before working in this unit, how many years of experience did you have in other ICUs?

_____ years _____ months (3:61-4)

3. How many years have you worked in this ICU?

_____ years _____ months (3:65-8)

4a. On which shift do you work the majority of your hours? (Please circle one only)

1. ____day (3:69)
2. ____night
3. ____evening
4. ____PM
5. ____weekend day
6. ____weekend night
7. ____rotating
8. ____flex

4b. How many hours (per day) is your normal shift?

_____ hours (3:70-1)

4c. How long have you worked on this shift?

_____ years _____ months (3:72-5)

5. Which nursing degrees do you hold? (Circle all that apply) (3:76-81)

1. ____LPN

2. ____diploma school

3. ____A.D. in nursing

4. ____B.S. in nursing

5. ____Masters in Nursing

6. ____Ph.D. in Nursing

6. Which of the following certifications do you have?

CCRN:

1. ___yes 2. ___no (3:82)

Hospital certification--critical care nursing

1. ___yes 2. ___no (3:83)

ACLS:

1. ___yes 2. ____no (3:84)

7a. When did you last participate in any continuing education related to ICU care?

1. ____in the last 7-12 months (3:85)

2. ____in the last 4-6 months

3. ____in the last 3 months

4. ____None of the above

7b. If within the last 12 months, briefly list and describe your continuing education.

1. (3:86-91)

2.

3.

4.

8. Did you participate in an orientation program specific to this intensive care unit when you began to work in the ICU?

1. ___yes 2. ___no (3:92)

9. Sex

1. ____Female 2. ____Male (3:93)

10. Marital status

1. ____Single (3:94)

2. ____Married

3. ____Divorced

4. ____Widowed

11. Number of children:_____ (3:95-6)

12. In what year were you born? 19_____ (3:97-8)

13. Which of the following applies? (3:99)

1. ___US native

2. ___US naturalized

3. ___Foreign national

4. ___Other

SECTION ELEVEN: IN CONCLUSION

1. In your judgment, what factors contribute to the effectiveness of this ICU? In other words, what are this ICU's particular strengths? (3:100-07)

2. In your judgment, what factors reduce this ICU's effectiveness? In other words, what factors need improvement? (3:108-15)

3. Consider the actual time you spent on this questionnaire; how long did it take you to complete this survey? (3:116)

____ (l) 30 minutes or less

____ (2) 30-40 minutes

____ (3) 40-50 minutes

____ (4) 50-60 minutes

____ (5) 60 minutes or more

4. The space below is provided for any additional comments you wish to make regarding your ICU in general or your personal experience with working in the unit. (3:117-24)

Thank you very much for your help and cooperation in answering this questionnaire! Please return in the addressed postage paid envelope provided.

THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

School of Public Health
University of California, Berkeley

Principal Investigator: **Stephen M. Shortell, Ph. D.**

Senior Investigators: **Denise M. Rousseau, Ph. D.**
Edward F. X. Hughes, M.D., M.P.H.

Project Director: **Robin R. Gillies, Ph. D.**

ICU Physician Questionnaire
(Long version)

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS
NATIONAL STUDY BACKGROUND INFORMATION

Overall Purpose

The questionnaire you are being asked to complete is part of a nation-wide study of the organization, management, and performance of intensive care units. The purpose of this study is to examine the organization and management practices of ICUs and their relationship to patient severity adjusted outcomes. A long term goal is to develop managerial and organizational guidelines which you and other hospitals can use to improve the quality of ICU care and reduce mortality. It is estimated that such improvements could save up to 10,000 lives a year.

Questionnaire Content

The questionnaires you have been given have been used successfully in many other organizational studies and have been extensively pre-tested. The questions are concerned with issues related to communication, coordination, conflict management, leadership, perceived unit team effectiveness, organizational culture, and related factors. Please keep in mind that questions pertaining to physicians refer to full and part-time salaried ICU physicians, house staff, and attending physicians who regularly admit to the ICU. We estimate that the questionnaire will take approximately 45 minutes to complete.

How You Benefit

Completion of these questions will be of direct benefit to you in two ways. First, we will provide you with specific feedback (in aggregate) on your unit's score on each of the measures of interest. Second, we will provide you with a comparison of your unit's score with that of the other hospitals in the study. This will enable you to assess your comparative performance. The feedback on your unit's scores and the comparison with other hospitals can be used to assess your performance and serve as a basis for continuous improvement of the quality of care provided in your unit.

Please Keep in Mind

You are asked to respond to each question as you believe the situation really exists, not as you think it should be or wish it to be. Responses are confidential; the numbers on the questionnaires are for tracking returns. Analyses will be based on aggregate responses only.

Please seal the completed questionnaire in the envelope provided and place it in the U.S. Post Office mail. Thank you for your assistance.

Please note: ANY QUESTIONS WHICH YOU HAVE OR ASSISTANCE NEEDED IN COMPLETING THIS QUESTIONNAIRE SHOULD BE DIRECTED TO ANY ONE OF THE FOLLOWING INDIVIDUALS.

Robin Gillies, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(708) 491-5540~~

Denise Rousseau, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(708) 491-8073, 491-3470~~

Stephen M. Shortell, Ph.D.
~~J.L. Kellogg Graduate School of Management~~
~~(708) 491-5540~~

SECTION ONE: RELATIONSHIPS AND COMMUNICATIONS WITHIN THE ICU

I. For each of the following statements, please circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
Physician-to-Physician Relationships: These statements refer to relationships between physicians.					
1. I look forward to working with the physicians of this ICU each day.	1	2	3	4	5
2. It is easy for me to talk openly with the physicians of this ICU.	1	2	3	4	5
3. I can think of a number of times when I received incorrect information from physicians in this unit.	1	2	3	4	5
4. There is effective communication between physicians across shifts.	1	2	3	4	5
5. Communication between physicians in this unit is very open.	1	2	3	4	5
6. It is often necessary for me to go back and check the accuracy of information I have received from physicians in this unit.	1	2	3	4	5
7. I find it enjoyable to talk with other physicians of this unit.	1	2	3	4	5
8. Physicians in the unit are well informed regarding events occuring on other shifts.	1	2	3	4	5
9. When physicians talk with each other in this unit, there is a good deal of understanding.	1	2	3	4	5
10. The accuracy of information passed among physicians of this unit leaves much to be desired.	1	2	3	4	5
11. It is easy to ask advice from physicians in this unit.	1	2	3	4	5
12. I feel that certain ICU physicians don't completely understand the information they receive.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
Nurse-to-Physician Relationships: These statements refer to relationships between nurses and physicians.					
13. I look forward to working with the nurses of this ICU each day.	1	2	3	4	5
14. It is easy for me to talk openly with the nurses of this ICU.	1	2	3	4	5
15. I can think of a number of times when I received incorrect information from nurses in this unit.	1	2	3	4	5
16. There is effective communication between nurses and physicians across shifts.	1	2	3	4	5
17. Communication between nurses and physicians in this unit is very open.	1	2	3	4	5
18. It is often necessary for me to go back and check the accuracy of information I have received from nurses in this unit.	1	2	3	4	5
19. I find it enjoyable to talk with nurses of this unit.	1	2	3	4	5
20. Nurses associated with the unit are well informed regarding events occuring on other shifts.	1	2	3	4	5
21. When nurses talk with physicians in this unit, there is a good deal of understanding.	1	2	3	4	5
22. The accuracy of information passed between nurses and physicians of this unit leaves much to be desired.	1	2	3	4	5
23. It is easy to ask advice from nurses in this unit.	1	2	3	4	5
24. I feel that certain ICU nurses don't completely understand the information they receive.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

General Relationships and Commmunications: These statements refer to general relationships and communications within the ICU.

25.	I get information on the status of patients when I need it.	1	2	3	4	5
26.	This ICU has goals and objectives different from my own.	1	2	3	4	5
27.	Physicians are readily available for consultation.	1	2	3	4	5
28.	When a patient's status changes, I get relevant information quickly.	1	2	3	4	5
29.	I take pride in being associated with this ICU.	1	2	3	4	5
30.	Nurses have a good understanding of physician goals.	1	2	3	4	5
31.	There are needless delays in relaying information regarding patient care.	1	2	3	4	5
32.	I identify with the goals and objectives of this ICU.	1	2	3	4	5
33.	Physicians have a good understanding of nursing objectives.	1	2	3	4	5
34.	I feel I am part of this ICU team.	1	2	3	4	5
35.	In matters pertaining to patient care, nurses call physicians in a timely manner.	1	2	3	4	5
36.	Nurses have a good understanding of physicians' treatment plans.	1	2	3	4	5
37.	If I had a chance to do the same kind of work for the same pay in another unit of this hospital, I wouldn't go.	1	2	3	4	5
38.	Nursing care plans are well understood by physicians in this unit.	1	2	3	4	5

39. Overall, how satisfied are you with the communications in this ICU? Circle the appropriate response.

	Very Dissat-isfied 1	Dissat-isfied 2	Neither Dissatisfied Nor Satisfied 3	Satisfied 4	Very Satisfied 5
(a) nurse-to-nurse	1	2	3	4	5
(b) physician-to-physician	1	2	3	4	5
(c) between nurses and physcians	1	2	3	4	5
(d) between patients and ICU nurses	1	2	3	4	5
(e) between patients and ICU physicians	1	2	3	4	5
(f) between patients' families and ICU nurses	1	2	3	4	5
(g) between patients' families and ICU physicians	1	2	3	4	5

40. How much say or influence do each of the following have over what goes on in this ICU? Circle the appropriate response. Circle "NA" if not applicable.

	No Influence At All	Little Influence	Moderate Influence	Very Great Influence	Great Influence	NA
Hospital Administrators	(l)	(2)	(3)	(4)	(5)	(8)
Staff Nurses	(l)	(2)	(3)	(4)	(5)	(8)
Charge Nurses	(l)	(2)	(3)	(4)	(5)	(8)
Nurse Clinicians	(l)	(2)	(3)	(4)	(5)	(8)
Clinical Coordinators	(l)	(2)	(3)	(4)	(5)	(8)
Assistant Nurse Manager	(l)	(2)	(3)	(4)	(5)	(8)
Nurse Manager/Head Nurse	(l)	(2)	(3)	(4)	(5)	(8)
Medical Director	(l)	(2)	(3)	(4)	(5)	(8)
House Physicians	(l)	(2)	(3)	(4)	(5)	(8)
Residents/Interns	(l)	(2)	(3)	(4)	(5)	(8)
Private Attending Physicians/ Private Admitters	(l)	(2)	(3)	(4)	(5)	(8)

SECTION TWO: THE WORKPLACE AND FACILITIES*

II. This section focuses on your ICU facility, the equipment and supplies you work with, and the procedures you use on your job.

Listed on the next two pages are sets of words which could be used to describe one's workplace, equipment, supplies, and procedures.

For each set of words, circle the box between them that best describes your situation at work. For example, if you think your workplace is clean some of the time, but not all of the time, you would circle...

Section Two items (34 items) have been deleted. These items are property of Human Synergistics. Please contact Human Synergistics for more information on items and/or their use.

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SECTION THREE: THE ICU CULTURE*

III. Please think about what it takes for you and people like yourself (e.g. your co-workers, people in similar positions) to "fit in" and meet expectations in this ICU. Using the following response options, please indicate the extent to which people are expected to:

Not At All 1	To A Slight Extent 2	To A Moderate Extent 3	To A Great Extent 4	To A Very Great Extent 5

Section Three items (48 items) have been deleted. These items are property of Human Synergistics. Please contact Human Synergistics for more information on items and/or their use.

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SECTION FOUR: TEAMWORK AND LEADERSHIP

IV. For each of the following statements, circle the number under the response that best reflect your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Nursing Leadership: These statements refer to your overall judgment of the characteristics of the ICU nursing leadership (i.e., nurse manager, assistant nurse manager, clinical nurse specialist, charge nurse; this excludes hospital administration). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

1.	ICU nursing leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
2.	ICU nursing leadership provides strong technical guidance and advice to unit physicians.	1	2	3	4	5
3.	ICU nursing leadership invites staff participation but usually makes decisions itself.	1	2	3	4	5
4.	ICU nursing leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
5.	To the extent possible, ICU nursing leadership delegates to unit members the opportunity to solve their own patient care problems.	1	2	3	4	5

	Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
6.	The ICU nursing leadership fails to make clear what they expect from unit members.	1	2	3	4	5
7.	Unit physicians look to ICU nursing leadership to help solve technical patient care problems.	1	2	3	4	5
8.	ICU nursing leadership actively directs group meetings designed to achieve unit objectives.	1	2	3	4	5
9.	ICU nursing leadership discourages physicians from taking initiative.	1	2	3	4	5
10.	Physicians in the unit are able to influence the thinking and behavior of ICU nursing leadership as much as ICU nursing leadership influences the thinking and behavior of unit physicians.	1	2	3	4	5
11.	Unit physicians are uncertain where they stand with the ICU nursing leadership.	1	2	3	4	5
12.	ICU nursing leadership is primarily provided through technical skill and knowledge.	1	2	3	4	5
13.	ICU nursing leadership shares but does not give up control over the decision-making process.	1	2	3	4	5
14.	The ICU nursing leadership is out of touch with physician perceptions and concerns.	1	2	3	4	5
15.	ICU nursing leadership is primarily exerted by making sure that the unit arrives at correct decisions.	1	2	3	4	5
16.	ICU nursing leadership is primarily characterized by encouraging people to solve their own problems.	1	2	3	4	5
17.	ICU nursing leadership often makes decisions without input from unit physicians.	1	2	3	4	5
18.	In this ICU, nursing leadership is primarily exerted through preventing and correcting technical mistakes.	1	2	3	4	5
19.	In this ICU, nursing leadership is primarily evidenced by giving staff opportunities for self-development.	1	2	3	4	5
20.	ICU nursing leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Physician Leadership: These statements refer to your overall judgment of the characteristics of the ICU physician leadership (i.e., ICU medical director and designated assistants or whichever physician is in charge of patient care). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

21. ICU physician leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
22. ICU physician leadership provides strong technical guidance and advice to physicians in the unit.	1	2	3	4	5
23. ICU physician leadership invites staff participation but usually makes decisions itself.	1	2	3	4	5
24. ICU physician leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
25. To the extent possible, ICU physician leadership delegates to individual physicians the opportunity to solve their own patient care problems.	1	2	3	4	5
26. The ICU physician leadership fails to make clear what they expect from unit members.	1	2	3	4	5
27. Unit physicians look to ICU physician leadership to help solve technical patient care problems.	1	2	3	4	5
28. ICU physician leadership actively directs group meetings designed to achieve unit objectives.	1	2	3	4	5
29. ICU physician leadership discourages physicians from taking initiative.	1	2	3	4	5
30. Physicians in the unit are able to influence the thinking and behavior of ICU physician leadership as much as ICU physician leadership influences the thinking and behavior of unit physicians.	1	2	3	4	5
31. Unit physicians are uncertain where they stand with the ICU physician leadership.	1	2	3	4	5
32. ICU physician leadership is primarily provided through technical skill and knowledge.	1	2	3	4	5
33. ICU physician leadership shares but does not give up control over the decision-making process.	1	2	3	4	5

Statement		Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
34.	The ICU physician leadership is out of touch with physician perceptions and concerns.	1	2	3	4	5
35.	ICU physician leadership is primarily exerted by making sure that the unit arrives at correct decisions.	1	2	3	4	5
36.	ICU physician leadership is primarily characterized by encouraging people to solve their own problems.	1	2	3	4	5
37.	ICU physician leadership often makes decisions without input from unit physicians.	1	2	3	4	5
38.	In this ICU, physician leadership is primarily exerted through preventing and correcting technical mistakes.	1	2	3	4	5
39.	In this ICU, physician leadership is primarily evidenced by giving staff opportunities for self-development.	1	2	3	4	5
40.	ICU physician leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

General: These statements refer in general to teamwork and leadership in the ICU.

41.	We rarely achieve much progress in unit meetings.	1	2	3	4	5
42.	Our unit has constructive work relationships with other groups in this hospital.	1	2	3	4	5
43.	Unit meetings seem to be disorganized.	1	2	3	4	5
44.	Our unit does not receive the cooperation it needs from other hospital units.	1	2	3	4	5
45.	Our meetings address and resolve the issues that should be dealt with.	1	2	3	4	5
46.	Other hospital subunits seem to have a low opinion of us.	1	2	3	4	5
47.	ICU interests are adequately represented at higher levels of the hospital.	1	2	3	4	5
48.	Inadequate working relationships with other hospital groups limit our effectiveness.	1	2	3	4	5

SECTION FIVE: PERCEIVED EFFECTIVENESS

V. For each of the following statements, circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
1. Our unit almost always meets its patient care treatment goals.	1	2	3	4	5
2. Given the severity of the patients we treat, our unit's patients experience very good outcomes.	1	2	3	4	5
3. Our unit does a good job of meeting family member needs.	1	2	3	4	5
4. Our unit does a good job of applying the most recently available technology to patient care needs.	1	2	3	4	5
5. We are able to recruit the best ICU nurses.	1	2	3	4	5
6. We do a good job of retaining ICU nurses in the unit.	1	2	3	4	5
7. We are able to recruit the best ICU physicians.	1	2	3	4	5
8. We do a good job of retaining ICU physicians in the unit.	1	2	3	4	5
9. Overall, our unit functions very well together as a team.	1	2	3	4	5
10. Our unit is very good at responding to emergency situations.	1	2	3	4	5

11. Relative to other ICUs within your area, how does your unit compare on the following items?

	Statement	Much Worse Than 1	Somewhat Worse Than 2	Same As 3	Somewhat Better Than 4	Much Better Than 5
a.	Meeting its patient care treatment goals.	1	2	3	4	5
b.	Patient care outcomes, taking into account patient severity	1	2	3	4	5
c.	Meeting family member needs.	1	2	3	4	5
d.	Applying the most recently available technology to patient care needs.	1	2	3	4	5
e.	Recruiting ICU nurses.	1	2	3	4	5
f.	Retaining ICU nurses.	1	2	3	4	5
g.	Recruiting ICU physicians.	1	2	3	4	5
h.	Retaining ICU physicians.	1	2	3	4	5

SECTION SIX--PART A: MANAGING DISAGREEMENTS BETWEEN PHYSICIANS

VI--PART A: Consider what happens when there is a disagreement or conflict between ICU physicians. Based on your experience in this unit, how likely is it that:

	Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost certain 5
1.	One physician will force others to yield to his or her position.	1	2	3	4	5
2.	Each physician involved will give in a bit and settle on a compromise.	1	2	3	4	5
3.	When physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
4.	When two physicians disagree, they will involve their superiors in resolving the issue.	1	2	3	4	5
5.	Physicians will withdraw from the conflict.	1	2	3	4	5
6.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
7.	A superior will have to resolve the dispute between physicians.	1	2	3	4	5
8.	All the physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
9.	A physician will try hard to win by pressing his or her position.	1	2	3	4	5
10.	The physicians involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
11.	A problem between physicians will be referred to someone higher up.	1	2	3	4	5
12.	Both parties will bargain away some of their desires in order to satisfy each other.	1	2	3	4	5
13.	Physicians on both sides will agree to a less than optimal solution.	1	2	3	4	5
14.	The physicians involved will take a firm position.	1	2	3	4	5
15.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
16.	Disagreements between physicians will be ignored or avoided.	1	2	3	4	5

SECTION SIX--PART B: MANAGING DISAGREEMENTS BETWEEN NURSES AND PHYSICIANS

VI--PART B: Consider what happens when there is a disagreement or conflict between ICU nurses and physicians. Based on your experience in this unit, how likely is it that:

	Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost Certain 5
1.	One will force others to yield to his or her position.	1	2	3	4	5
2.	Nurses and physicians involved will give in a bit and settle on a compromise.	1	2	3	4	5
3.	When nurses and physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
4.	When nurses and physicians disagree, they will involve their superiors in resolving the issue.	1	2	3	4	5
5.	Both parties will withdraw from the conflict.	1	2	3	4	5
6.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
7.	A superior will have to resolve the dispute between nurses and physicians.	1	2	3	4	5
8.	The nurses and physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
9.	Each will try hard to win by pressing his or her position.	1	2	3	4	5
10.	Both parties involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
11.	A problem between nurses and physicians will be referred to someone higher up.	1	2	3	4	5
12.	Both parties will bargain away some of their desires in order to satisfy each other.	1	2	3	4	5
13.	Nurses and physicians will agree to a less than optimal solution.	1	2	3	4	5
14.	Both parties involved will take a firm position.	1	2	3	4	5
15.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
16.	Disagreements between nurses and physicians will be ignored or avoided.	1	2	3	4	5

SECTION SEVEN: COORDINATION MECHANISMS

WITHIN THE ICU

VII--PART A: Various strategies and procedures can be used to coordinate patient care activities within an ICU. In your ICU, to what extent do each of the mechanisms listed below effectively contribute to the coordination of staff activities and the quality of patient care? Circle the appropriate response below. Please circle "8" if your ICU does not use the mechanism.

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Effective 4	Very Effective 5	Not Applicable (Not Used Here) 8
a. Written rules, policies, and procedures?	1	2	3	4	5	8
b. Written plans and schedules?	1	2	3	4	5	8
c. Computerized information systems?	1	2	3	4	5	8
d. Unit directors' efforts to coordinate member activities?	1	2	3	4	5	8
e. One-to-one communication between staff?	1	2	3	4	5	8
f. Ad hoc group meetings?	1	2	3	4	5	8
g. Task forces and standing committees?	1	2	3	4	5	8
h. Written treatment protocols?	1	2	3	4	5	8
i. Daily staff rounds?	1	2	3	4	5	8

BETWEEN THE ICU AND OTHER HOSPITAL UNITS

VII--PART B: Various strategies and procedures can also be used to coordinate patient care activities between your ICU and other hospital units(e.g., operating room, emergency room, general medical/surgical floors, lab, respiratory therapy, etc.). In your ICU, to what extent do each of the mechanisms listed below effectively contribute to the coordination of your unit's activities with other hospital units? Circle the appropriate response below. Please circle "8" if your ICU does not use the mechanism.

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Effective 4	Very Effective 5	Not Applicable (Not Used Here) 8
a. Written treatment protocols?	1	2	3	4	5	8
b. Ad hoc group meetings between ICU members and members of other units?	1	2	3	4	5	8

Statement	Not at all Effective 1	Slightly Effective 2	Moderately Effective 3	Effective 4	Very Effective 5	Not Applicable (Not Used Here) 8
c. Unit directors' personal efforts to coordinate activities between ICU staff and members of other units?	1	2	3	4	5	8
d. Written rules, policies, and procedures?	1	2	3	4	5	8
e. Written plans and schedules?	1	2	3	4	5	8
f. One-to-one communication between ICU staff and members of other units?	1	2	3	4	5	8
g. Task forces and standing committees involving members of the ICU and other units?	1	2	3	4	5	8
h. Daily staff rounds in which information is shared which helps assure coordination between other units and the ICU?	1	2	3	4	5	8
i. Computerized information systems?	1	2	3	4	5	8

SECTION EIGHT: AUTHORITY

VIII. For each of the following statements, circle the number on the scale which best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
A. Our ICU Medical Director has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing physician staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
B. The ICU Medical Director does a good job of involving members in:					
(l) Determining standards for patient care	1	2	3	4	5
(2) Determining staffing requirements	1	2	3	4	5
(3) Developing quality assurance programs	1	2	3	4	5
(4) Assuring that standards are met and corrective actions taken	1	2	3	4	5
(5) Researching, testing, and implementing changes	1	2	3	4	5
(6) Determining nursing staff patterns (e.g. primary/team/functional)	1	2	3	4	5
(7) Developing budgets based on staff objectives	1	2	3	4	5
C. Our ICU Nurse Manager/Head Nurse has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5
D. Our ICU Nurse Manager/Head Nurse does a good job of involving members in:					
(l) Determining standards for patient care	1	2	3	4	5
(2) Determining staffing requirements	1	2	3	4	5
(3) Developing quality assurance programs	1	2	3	4	5
(4) Assuring that standards are met and corrective actions taken	1	2	3	4	5
(5) Researching, testing, and implementing changes	1	2	3	4	5
(6) Determining nursing staff patterns (e.g. primary/team/functional)	1	2	3	4	5
(7) Developing budgets based on staff objectives	1	2	3	4	5

SECTION NINE: SATISFACTION

IX. Overall, how satisfied are you in your job? Circle the appropriate response.

Very Dissatisfied	Dissatisfied	Neither Dissatisfied Nor Satisfied	Satisfied	Very Satisfied
1	2	3	4	5

SECTION TEN: BACKGROUND INFORMATION

1. What is your position in the ICU? (Check one only)
   1. ___ Resident/Intern
   2. ___ Full-time salaried in unit (not a resident)
   3. ___ Part-time salaried in unit (not a resident)
   4. ___ Per Diem Physician
   5. ___ Attending physician/private admitter

2a. On average, approximately how many patients a year do you admit to this ICU? _____

2b. Do you have admitting privileges at any other hospitals in the area?
   1. ___ yes
   2. ___ no

2c. Do you admit any of your patients to the ICUs at other hospitals?
   1. ___ yes
   2. ___ no

3a. What is your specialty? _____

3b. Are you board certified in this specialty?
   1. ___ yes
   2. ___ no

4a. What is your subspecialty? _____

4b. Are you board certified in this subspecialty?
   1. ___ yes
   2. ___ no

5. List other specialties relevant to ICU care.

1.

2.

3.

4.

6. Before working in this unit, how many years of experience did you have in other ICUs?

_____ years

7. How many years have you worked in or admitted patients to this ICU?

_____ years

8a. When did you last participate in any continuing education related to ICU care?

1. ___ in the last 7-12 months

2. ___ in the last 4-6 months

3. ___ in the last 3 months

4. ___ None of the above

8b. If within the last 12 months, briefly list your continuing education.

1.

2.

3.

4.

9. Do you have a daily routine visiting time for the ICU?

1. ___ yes

2. ___ no

10. Did you participate in an orientation program to this unit when you began to work in or admit patients to the ICU?

1. ___ yes

2. ___ no

11. Sex

1. ___ Female

2. ___ Male

12. Marital status

1. ___ Single

2. ___ Married

3. ___ Divorced

4. ___ Widowed

13. Number of children: _____

14. In what year were you born? 19_____

15. Which of the following applies? (Check one only)

1. ___ US native

2. ___ US naturalized

3. ___ Foreign national

4. ___ Other

SECTION ELEVEN: IN CONCLUSION

1. In your judgment, what factors contribute to the effectiveness of this ICU? In other words, what are this ICU's particular strengths?

2. In your judgment, what factors reduce this ICU's effectiveness? In other words, what factors need improvement?

3. Consider the actual time you spent on this questionnaire. How long did it take you to complete this survey?

_____ (l) 30 minutes or less

_____ (2) 30-40 minutes

_____ (3) 40-50 minutes

_____ (4) 50-60 minutes

_____ (5) 60 minutes or more

4. The space below is provided for any additional comments you wish to make regarding your ICU in general or your personal experience with working in the unit.

Thank you very much for your help and cooperation in answering this questionnaire! Please return in the addressed postage paid envelope provided.

Robin Gillies, Ph.D.
~~Program in Hospital and Health Services Management~~
~~Kellogg Graduate School of Management~~
~~Northwestern University~~
~~2001 Sheridan Road - Leverone Hall~~
~~Evanston, IL 60201~~

Measure # 12b: ICU Nurse-Physician Questionnaire – Short Versions

Contact Information:

- For questions regarding this measure and for permission to use it, contact either:

Stephen M. Shortell
Dean and Professor
School of Public Health
University of California, Berkeley
50 University Hall #7360
Berkeley, CA 94720-7360, USA
shortell@berkeley.edu

or:

Dr. Denise M. Rousseau
University Professor
Carnegie Mellon University
H.J. Heinz II Professor of Organizational Behavior and Public Policy
Heinz College and Tepper School of Business
P: (412) 268-8470
rousseau@andrew.cmu.edu

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

School of Public Health
University of California, Berkeley

Principal Investigator: **Stephen M. Shortell, Ph. D.**

Senior Investigators: **Denise M. Rousseau, Ph. D.**
Edward F. X. Hughes, M.D., M.P.H.

Project Director: **Robin R. Gillies, Ph. D.**

ICU Nurse Questionnaire
(Short version)

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INFORMATION FOR USERS OF THE ICU NURSE-PHYSICIAN QUESTIONNAIRE

This instrument was developed for use in intensive care units. Information regarding the psychometric characteristics of the instrument in the National Study of Intensive Care Units is available in S. Shortell *et al*, "Organizational Assessment in Intensive Care Units (ICUs): Construct Development, Reliability, and Validity of the ICU Nurse-Physician Questionnaire," Medical Care, Volume 29, August 1991, pp 709-727. The scales developed from the items in this questionnaire are also detailed in the Medical Care article. The results of the study are reported in S. Shortell *et al*, "The Performance of Intensive Care Units: Does Good Management Make a Difference?" Medical Care, Volume 32:5, May 1995, pp 508-525.

Although originally designed for ICUs, we believe the questionnaire can be used in other hospital settings (units). However, use in other settings will require that the specified unit of interest be changed throughout the questionnaire. For example, "It is easy for me to talk openly with the nurses of this ICU" can be changed to "It is easy for me to talk openly with the nurses of this ER" for evaluating an emergency room or "It is easy for me to talk openly with the nurses who work with coronary artery bypass graft patients" for evaluating a coronary bypass patient critical pathway. We believe this can be done without jeopardizing the reliability and validity of the questionnaire, and subsequent use by other researchers seems to support this belief.

On the next page is the background information discussion from the questionnaire that may serve as a guide for your own set of instructions to potential respondents. Indicating how the respondent will benefit from the completion of the questionnaire is important for promoting response. We also found it useful to include a paragraph such as "Please Keep in Mind" to alleviate any concerns about the consequences of providing the information requested.

Overall, the questionnaire should take approximately 20 minutes to complete. You may want to add on a section requesting relevant background information (education, position, experience, full-time/part-time, shift, certification/specialties, sex, age, citizenship, etc.) on the respondent. You may also want to include a section for open-ended questions or comments.

If you wish to use the ICU Nurse-Physician Questionnaire, please send/fax a written request to Stephen M. Shortell, Ph.D., c/o Robin Gillies, using the contact information listed below. Formal permission will be quickly granted. There is no cost for use of the instrument for research purposes. In exchange for permission to use the questionnaire for research purposes, we request that it be cited in any publications and research materials that result from your research. The proper citation for use is: "Excerpted from The Organization and Management of Intensive Care Units. Copyright 1989, Shortell and Rousseau." Again, it is permissible to adapt the instruments to suit your specific situation. We do request, however, that you share your findings from the use of the instrument with us.

If you have any questions regarding the instruments, please contact Robin Gillies, Ph.D., at Health Policy and Management, School of Public Health, 140 Warren Hall, University of California, Berkeley, CA 94720-7360 (Tel: 510/643-8063; FAX: 510/643-8613; e-mail:gillies@uclink4.Berkeley.edu).

THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS
NATIONAL STUDY BACKGROUND INFORMATION

Overall Purpose

The questionnaire you are being asked to complete is part of a nation-wide study of the organization, management, and performance of intensive care units. The purpose of this study is to examine the organization and management practices of ICUs and their relationship to patient severity adjusted outcomes. A long-term goal is to develop managerial and organizational guidelines that you and other hospitals can use to improve the quality of ICU care and reduce mortality. It is estimated that such improvements could save up to 10,000 lives a year.

Questionnaire Content

The questionnaires you have been given have been used successfully in many other organizational studies and have been extensively pre-tested. The questions are concerned with issues related to communication, coordination, conflict management, leadership, perceived unit team effectiveness, and related factors. Please keep in mind that questions pertaining to physicians refer to full and part-time salaried ICU physicians, house staff, and attending physicians who regularly admit to the ICU. We estimate that the questionnaire will take approximately 20 minutes to complete.

How You Benefit

Completion of these questions will be of direct benefit to you in two ways. First, we will provide you with specific feedback (in aggregate) on your unit's score on each of the measures of interest. Second, we will provide you with a comparison of your unit's score with that of the other hospitals in the study. This will enable you to assess your comparative performance. The feedback on your unit's scores and the comparison with other hospitals can be used to assess your performance and serve as a basis for continuous improvement of the quality of care provided in your unit.

Please Keep in Mind

You are asked to respond to each question as you believe the situation really exists, not as you think it should be or wish it to be. Responses are confidential; the numbers on the questionnaires are for tracking returns. Analyses will be based on aggregate responses only.

Please seal the completed questionnaire in the envelope provided and place it in the U.S. Post Office mail. Thank you for your assistance.

Please note: ANY QUESTIONS WHICH YOU HAVE OR ASSISTANCE NEEDED IN COMPLETING THIS QUESTIONNAIRE SHOULD BE DIRECTED TO ANY ONE OF THE FOLLOWING INDIVIDUALS.

Robin Gillies, Ph.D.
J.L. Kellogg Graduate School of Management
(847) 491-5540 ***(No longer valid)***

Denise Rousseau, Ph.D.
Carnegie-Mellon Universiry
(412) 268-8470 ***(No longer valid)***

Stephen M. Shortell, Ph.D.
J.L. Kellogg Graduate School of Management
(847) 491-5540 ***(No longer valid)***

SECTION ONE: RELATIONSHIPS AND COMMUNICATIONS WITHIN THE ICU

I. For each of the following statements, please circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
Nurse-to-Nurse Relationships: These statements refer to relationships between nurses.					
1. It is easy for me to talk openly with the nurses of this ICU.	1	2	3	4	5
2. I can think of a number of times when I received incorrect information from nurses in this unit.	1	2	3	4	5
3. Communication between nurses in this unit is very open.	1	2	3	4	5
4. It is often necessary for me to go back and check the accuracy of information I have received from nurses in this unit.	1	2	3	4	5
5. I find it enjoyable to talk with other nurses of this unit.	1	2	3	4	5
6. When nurses talk with each other in this unit, there is a good deal of understanding.	1	2	3	4	5
7. The accuracy of information passed among nurses of this unit leaves much to be desired.	1	2	3	4	5
8. It is easy to ask advice from nurses in this unit.	1	2	3	4	5
9. I feel that certain ICU nurses don't completely understand the information they receive.	1	2	3	4	5
Nurse-to-Physician Relationships: These statements refer to relationships between nurses and physicians.					
10. It is easy for me to talk openly with the physicians of this ICU.	1	2	3	4	5
11. I can think of a number of times when I received incorrect information from physicians in this unit.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
12. Communication between nurses and physicians in this unit is very open.	1	2	3	4	5
13. It is often necessary for me to go back and check the accuracy of information I have received from physicians in this unit.	1	2	3	4	5
14. I find it enjoyable to talk with physicians of this unit.	1	2	3	4	5
15. When nurses talk with physicians in this unit, there is a good deal of understanding.	1	2	3	4	5
16. The accuracy of information passed between nurses and physicians of this unit leaves much to be desired.	1	2	3	4	5
17. It is easy to ask advice from physicians in this unit.	1	2	3	4	5
18. I feel that certain ICU physicians don't completely understand the information they receive.	1	2	3	4	5

General Relationships and Commmunications: These statements refer to general relationships and communications within the ICU.

19. I get information on the status of patients when I need it.	1	2	3	4	5
20. When a patient's status changes, I get relevant information quickly.	1	2	3	4	5
21. There are needless delays in relaying information regarding patient care.	1	2	3	4	5
22. In matters pertaining to patient care, nurses call physicians in a timely manner.	1	2	3	4	5

SECTION TWO: TEAMWORK AND LEADERSHIP

II. For each of the following statements, circle the number under the response that best reflect your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Nursing Leadership: These statements refer to your overall judgment of the characteristics of the ICU nursing leadership (i.e., nurse manager, assistant nurse manager, clinical nurse specialist, charge nurse; this excludes hospital administration). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

1.	ICU nursing leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
2.	ICU nursing leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
3.	The ICU nursing leadership fails to make clear what they expect from members.	1	2	3	4	5
4.	ICU nursing leadership discourages nurses from taking initiative.	1	2	3	4	5
5.	Unit nurses are uncertain where they stand with the ICU nursing leadership.	1	2	3	4	5
6.	The ICU nursing leadership is out of touch with nurse perceptions and concerns.	1	2	3	4	5
7.	ICU nursing leadership often makes decisions without input from unit nurses.	1	2	3	4	5
8.	ICU nursing leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Physician Leadership: These statements refer to your overall judgment of the characteristics of the ICU physician leadership (i.e., ICU medical director and designated assistants or whichever physician is in charge of patient care). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

9.	ICU physician leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
10.	ICU physician leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
11.	The ICU physician leadership fails to make clear what they expect from members.	1	2	3	4	5
12.	ICU physician leadership discourages nurses from taking initiative.	1	2	3	4	5
13.	Unit nurses are uncertain where they stand with the ICU physician leadership.	1	2	3	4	5
14.	The ICU physician leadership is out of touch with nurse perceptions and concerns.	1	2	3	4	5
15.	ICU physician leadership often makes decisions without input from unit nurses.	1	2	3	4	5
16.	ICU physician leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

General: These statements refer in general to teamwork and leadership in the ICU.

17.	Our unit has constructive work relationships with other groups in this hospital.	1	2	3	4	5
18.	Our unit does not receive the cooperation it needs from other hospital units.	1	2	3	4	5
19.	Other hospital subunits seem to have a low opinion of us.	1	2	3	4	5
20.	Inadequate working relationships with other hospital groups limit our effectiveness.	1	2	3	4	5

SECTION THREE: PERCEIVED EFFECTIVENESS

III. For each of the following statements, circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
1. Our unit almost always meets its patient care treatment goals.	1	2	3	4	5
2. Given the severity of the patients we treat, our unit's patients experience very good outcomes.	1	2	3	4	5
3. Our unit does a good job of meeting family member needs.	1	2	3	4	5
4. Our unit does a good job of applying the most recently available technology to patient care needs.	1	2	3	4	5
5. We are able to recruit the best ICU nurses.	1	2	3	4	5
6. We do a good job of retaining ICU nurses in the unit.	1	2	3	4	5
7. We are able to recruit the best ICU physicians.	1	2	3	4	5
8. We do a good job of retaining ICU physicians in the unit.	1	2	3	4	5
9. Overall, our unit functions very well together as a team.	1	2	3	4	5
10. Our unit is very good at responding to emergency situations.	1	2	3	4	5

11. Relative to other ICUs within your area, how does your unit compare on the following items?

	Much Worse Than	Somewhat Worse Than	Same As	Somewhat Better Than	Much Better Than
)					
a. Meeting its patient care treatment goals.	1	2	3	4	5
b. Patient care outcomes, taking into account patient severity	1	2	3	4	5
c. Meeting family member needs.	1	2	3	4	5
d. Applying the most recently available technology to patient care needs.	1	2	3	4	5
e. Recruiting ICU nurses.	1	2	3	4	5
f. Retaining ICU nurses.	1	2	3	4	5
g. Recruiting ICU physicians.	1	2	3	4	5

h. Retaining ICU physicians.	1	2	3	4	5

SECTION FOUR--PART A: MANAGING DISAGREEMENTS BETWEEN NURSES

IV--PART A: Consider what happens when there is a disagreement or conflict between ICU nurses. Based on your experience in this unit, how likely is it that:

	Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost certain 5
1.	When nurses disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
2.	Nurses will withdraw from the conflict.	1	2	3	4	5
3.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
4.	All the nurses will work hard to arrive at the best possible solution.	1	2	3	4	5
5.	The nurses involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
6.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
7.	Disagreements between nurses will be ignored.	1	2	3	4	5

SECTION FOUR--PART B: MANAGING DISAGREEMENTS BETWEEN NURSES AND PHYSICIANS

IV--PART B: Consider what happens when there is a disagreement or conflict between ICU nurses and physicians. Based on your experience in this unit, how likely is it that:

1.	When nurses and physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
2.	Both parties will withdraw from the conflict.	1	2	3	4	5
3.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
4.	The nurses and physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
5.	Both parties involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
6.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
7.	Disagreements between nurses and physicians will be ignored.	1	2	3	4	5

SECTION FIVE: AUTHORITY

V. For each of the following statements, circle the number on the scale which best reflects your judgment.

Statement	**Strongly Disagree 1**	**Disagree 2**	**Neither Agree Nor Disagree 3**	**Agree 4**	**Strongly Agree 5**
A. Our ICU Medical Director has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing physician staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5
B. Our ICU Nurse Manager/Head Nurse has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5

SECTION SIX: SATISFACTION

VI. Overall, how satisfied are you in your job? Circle the appropriate response.

Very Dissat-isfied 1	Dissat-isfied 2	Neither Dissatisfied Nor Satisfied 3	Satisfied 4	Very Satisfied 5

Thank you very much for your help and cooperation in answering this questionnaire! Please return in the addressed postage paid envelope provided.

THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

School of Public Health
University of California, Berkeley

Principal Investigator: **Stephen M. Shortell, Ph. D.**

Senior Investigators: **Denise M. Rousseau, Ph. D.**
Edward F. X. Hughes, M.D., M.P.H.

Project Director: **Robin R. Gillies, Ph. D.**

ICU Physician Questionnaire
(Short Version)

Copyright Shortell and Rousseau, 1989

INFORMATION FOR USERS OF THE ICU NURSE-PHYSICIAN QUESTIONNAIRE

This instrument was developed for use in intensive care units. Information regarding the psychometric characteristics of the instrument in the National Study of Intensive Care Units is available in S. Shortell *et al*, "Organizational Assessment in Intensive Care Units (ICUs): Construct Development, Reliability, and Validity of the ICU Nurse-Physician Questionnaire," Medical Care , Volume 29, August 1991, pp 709-727. The scales developed from the items in this questionnaire are also detailed in the Medical Care article.

Although originally designed for ICUs, we believe the questionnaire can be used in other hospital settings (units). However, use in other settings will require that the specified unit of interest be changed throughout the questionnaire. For example, "It is easy for me to talk openly with the physicians of this ICU" can be changed to "It is easy for me to talk openly with the physicians of this ER" for evaluating an emergency room or "It is easy for me to talk openly with the physicians who work with coronary artery bypass graft patients" for evaluating a coronary bypass patient critical pathway. We believe this can be done without jeopardizing the reliability and validity of the questionnaire, and subsequent use by other researchers seems to support this belief.

On the next page is the background information discussion from the questionnaire that may serve as a guide for your own set of instructions to potential respondents. Indicating how the respondent will benefit from the completion of the questionnaire is important for promoting response. We also found it useful to include a paragraph such as "Please Keep in Mind" to alleviate any concerns about the consequences of providing the information requested.

Overall, the questionnaire should take approximately 20 minutes to complete. You may want to add on a section requesting relevant background information (education, position, experience, full-time/part-time, shift, certification/specialties, sex, age, citizenship, etc.) on the respondent. You may also want to include a section for open-ended questions or comments.

If you wish to use the ICU Nurse-Physician Questionnaire, please send/fax a written request to Stephen M. Shortell, Ph.D., c/o Robin Gillies, Health Policy and Management, School of Public Health, 140 Warren Hall, University of California, Berkeley, CA 94720-7360 (Tel: 510/643-8063; FAX: 510/643-8613). Formal permission will be quickly granted. There is no cost for use of the instrument for research purposes. In exchange for permission to use the questionnaire for research purposes, we request that it be cited in any publications and research materials that result from your research. The proper citation for use is: "Excerpted from The Organization and Management of Intensive Care Units. Copyright 1989, Shortell and Rousseau." Again, it is permissible to adapt the instruments to suit your specific situation. We do request, however, that you share your findings from the use of the instrument with us.

If you have any questions regarding the instruments, please contact Robin Gillies, Ph.D., at Health Policy and Management, School of Public Health, 140 Warren Hall, University of California, Berkeley, CA 94720-7360 (Tel: 510/643-8063; FAX: 510/643-8613).

THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS
NATIONAL STUDY BACKGROUND INFORMATION

Overall Purpose

The questionnaire you are being asked to complete is part of a nation-wide study of the organization, management, and performance of intensive care units. The purpose of this study is to examine the organization and management practices of ICUs and their relationship to patient severity adjusted outcomes. A long term goal is to develop managerial and organizational guidelines which you and other hospitals can use to improve the quality of ICU care and reduce mortality. It is estimated that such improvements could save up to 10,000 lives a year.

Questionnaire Content

The questionnaires you have been given have been used successfully in many other organizational studies and have been extensively pre-tested. The questions are concerned with issues related to communication, coordination, conflict management, leadership, perceived unit team effectiveness, organizational culture, and related factors. Please keep in mind that questions pertaining to physicians refer to full and part-time salaried ICU physicians, house staff, and attending physicians who regularly admit to the ICU. We estimate that the questionnaire will take approximately 20 minutes to complete.

How You Benefit

Completion of these questions will be of direct benefit to you in two ways. First, we will provide you with specific feedback (in aggregate) on your unit's score on each of the measures of interest. Second, we will provide you with a comparison of your unit's score with that of the other hospitals in the study. This will enable you to assess your comparative performance. The feedback on your unit's scores and the comparison with other hospitals can be used to assess your performance and serve as a basis for continuous improvement of the quality of care provided in your unit.

Please Keep in Mind

You are asked to respond to each question as you believe the situation really exists, not as you think it should be or wish it to be. Responses are confidential; the numbers on the questionnaires are for tracking returns. Analyses will be based on aggregate responses only.

Please seal the completed questionnaire in the envelope provided and place it in the U.S. Post Office mail. Thank you for your assistance.

Please note: ANY QUESTIONS WHICH YOU HAVE OR ASSISTANCE NEEDED IN COMPLETING THIS QUESTIONNAIRE SHOULD BE DIRECTED TO ANY ONE OF THE FOLLOWING INDIVIDUALS.

Robin Gillies, Ph.D.
J.L. Kellogg Graduate School of Management
(847) 491-5540

Denise Rousseau, Ph.D.
J.L. Kellogg Graduate School of Management
(847) 491-8073, 491-3470

Stephen M. Shortell, Ph.D.
J.L. Kellogg Graduate School of Management
(847) 491-5540

SECTION ONE: RELATIONSHIPS AND COMMUNICATIONS WITHIN THE ICU

I. For each of the following statements, please circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
Physician-to-Physician Relationships: These statements refer to relationships between physicians.					
1. It is easy for me to talk openly with the physicians of this ICU.	1	2	3	4	5
2. I can think of a number of times when I received incorrect information from physicians in this unit.	1	2	3	4	5
3. Communication between physicians in this unit is very open.	1	2	3	4	5
4. It is often necessary for me to go back and check the accuracy of information I have received from physicians in this unit.	1	2	3	4	5
5. I find it enjoyable to talk with other physicians of this unit.	1	2	3	4	5
6. When physicians talk with each other in this unit, there is a good deal of understanding.	1	2	3	4	5
7. The accuracy of information passed among physicians of this unit leaves much to be desired.	1	2	3	4	5
8. It is easy to ask advice from physicians in this unit.	1	2	3	4	5
9. I feel that certain ICU physicians don't completely understand the information they receive.	1	2	3	4	5
Nurse-to-Physician Relationships: These statements refer to relationships between nurses and physicians.					
10. It is easy for me to talk openly with the nurses of this ICU.	1	2	3	4	5
11. I can think of a number of times when I received incorrect information from nurses in this unit.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
12. Communication between nurses and physicians in this unit is very open.	1	2	3	4	5
13. It is often necessary for me to go back and check the accuracy of information I have received from nurses in this unit.	1	2	3	4	5
14. I find it enjoyable to talk with nurses of this unit.	1	2	3	4	5
15. When nurses talk with physicians in this unit, there is a good deal of understanding.	1	2	3	4	5
16. The accuracy of information passed between nurses and physicians of this unit leaves much to be desired.	1	2	3	4	5
17. It is easy to ask advice from nurses in this unit.	1	2	3	4	5
18. I feel that certain ICU nurses don't completely understand the information they receive.	1	2	3	4	5

General Relationships and Commmunications: These statements refer to general relationships and communications within the ICU.

19. I get information on the status of patients when I need it.	1	2	3	4	5
20. When a patient's status changes, I get relevant information quickly.	1	2	3	4	5
21. There are needless delays in relaying information regarding patient care.	1	2	3	4	5
22. In matters pertaining to patient care, nurses call physicians in a timely manner.	1	2	3	4	5

SECTION TWO: TEAMWORK AND LEADERSHIP

II. For each of the following statements, circle the number under the response that best reflect your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Nursing Leadership: These statements refer to your overall judgment of the characteristics of the ICU nursing leadership (i.e., nurse manager, assistant nurse manager, clinical nurse specialist, charge nurse; this excludes hospital administration). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

1.	ICU nursing leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
2.	ICU nursing leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
3.	The ICU nursing leadership fails to make clear what they expect from unit members.	1	2	3	4	5
4.	ICU nursing leadership discourages physicians from taking initiative.	1	2	3	4	5
5.	Unit physicians are uncertain where they stand with the ICU nursing leadership.	1	2	3	4	5
6.	The ICU nursing leadership is out of touch with physician perceptions and concerns.	1	2	3	4	5
7.	ICU nursing leadership often makes decisions without input from unit physicians.	1	2	3	4	5
8.	ICU nursing leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5

Physician Leadership: These statements refer to your overall judgment of the characteristics of the ICU physician leadership (i.e., ICU medical director and designated assistants or whichever physician is in charge of patient care). "Unit physicians" refers to all full and part time ICU physicians, house staff, and attending physicians who regularly admit patients to the ICU. The terms "staff" and "unit members" refer to all nurses and physicians associated with the unit.

9.	ICU physician leadership emphasizes standards of excellence to the staff.	1	2	3	4	5
10.	ICU physician leadership is sufficiently sensitive to the different needs of unit members.	1	2	3	4	5
11.	The ICU physician leadership fails to make clear what they expect from unit members.	1	2	3	4	5
12.	ICU physician leadership discourages physicians from taking initiative.	1	2	3	4	5
13.	Unit physicians are uncertain where they stand with the ICU physician leadership.	1	2	3	4	5
14.	The ICU physician leadership is out of touch with physician perceptions and concerns.	1	2	3	4	5
15.	ICU physician leadership often makes decisions without input from unit physicians.	1	2	3	4	5
16.	ICU physician leadership effectively adapts its problem-solving style to changing circumstances.	1	2	3	4	5

General: These statements refer in general to teamwork and leadership in the ICU.

17.	Our unit has constructive work relationships with other groups in this hospital.	1	2	3	4	5
18.	Our unit does not receive the cooperation it needs from other hospital units.	1	2	3	4	5
19.	Other hospital subunits seem to have a low opinion of us.	1	2	3	4	5
20.	Inadequate working relationships with other hospital groups limit our effectiveness.	1	2	3	4	5

SECTION THREE: PERCEIVED EFFECTIVENESS

III. For each of the following statements, circle the number under the response that best reflects your judgment.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
1. Our unit almost always meets its patient care treatment goals.	1	2	3	4	5
2. Given the severity of the patients we treat, our unit's patients experience very good outcomes.	1	2	3	4	5
3. Our unit does a good job of meeting family member needs.	1	2	3	4	5
4. Our unit does a good job of applying the most recently available technology to patient care needs.	1	2	3	4	5
5. We are able to recruit the best ICU nurses.	1	2	3	4	5
6. We do a good job of retaining ICU nurses in the unit.	1	2	3	4	5
7. We are able to recruit the best ICU physicians.	1	2	3	4	5
8. We do a good job of retaining ICU physicians in the unit.	1	2	3	4	5
9. Overall, our unit functions very well together as a team.	1	2	3	4	5
10. Our unit is very good at responding to emergency situations.	1	2	3	4	5

11. Relative to other ICUs within your area, how does your unit compare on the following items?

	Much Worse Than	Somewhat Worse Than	Same As	Somewhat Better Than	Much Better Than
					(2:83)
a. Meeting its patient care treatment goals.	1	2	3	4	5
b. Patient care outcomes, taking into account patient severity	1	2	3	4	5
c. Meeting family member needs.	1	2	3	4	5
d. Applying the most recently available technology to patient care needs.	1	2	3	4	5
e. Recruiting ICU nurses.	1	2	3	4	5
f. Retaining ICU nurses.	1	2	3	4	5
g. Recruiting ICU physicians.	1	2	3	4	5

h. Retaining ICU physicians.	1	2	3	4	5

SECTION FOUR--PART A: MANAGING DISAGREEMENTS BETWEEN PHYSICIANS

IV--PART A: Consider what happens when there is a disagreement or conflict between ICU physicians. Based on your experience in this unit, how likely is it that:

	Statement	Not at all likely 1	Not so likely 2	Somewhat likely 3	Very likely 4	Almost certain 5
1.	When physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
2.	Physicians will withdraw from the conflict.	1	2	3	4	5
3.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
4.	All the physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
5.	The physicians involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
6.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5
7.	Disagreements between physicians will be ignored or avoided.	1	2	3	4	5

SECTION FOUR--PART B: MANAGING DISAGREEMENTS BETWEEN NURSES AND PHYSICIANS

IV--PART B: Consider what happens when there is a disagreement or conflict between ICU nurses and physicians. Based on your experience in this unit, how likely is it that:

1.	When nurses and physicians disagree, they will ignore the issue, pretending it will "go away."	1	2	3	4	5
2.	Both parties will withdraw from the conflict.	1	2	3	4	5
3.	All points of view will be carefully considered in arriving at the best solution of the problem.	1	2	3	4	5
4.	The nurses and physicians will work hard to arrive at the best possible solution.	1	2	3	4	5
5.	Both parties involved will not settle the dispute until all are satisfied with the decision.	1	2	3	4	5
6.	Everyone contributes from their experience and expertise to produce a high quality solution.	1	2	3	4	5

7.	Disagreements between nurses and physicians will be ignored or avoided.	1	2	3	4	5

SECTION FIVE: AUTHORITY

V. For each of the following statements, circle the number on the scale which best reflects your judgment.

Statement	**Strongly Disagree 1**	**Disagree 2**	**Neither Agree Nor Disagree 3**	**Agree 4**	**Strongly Agree 5**
A. Our ICU Medical Director has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing physician staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5
B. Our ICU Nurse Manager/Head Nurse has sufficient authority regarding:					
(l) Admitting and discharging patients	1	2	3	4	5
(2) Treatment protocols	1	2	3	4	5
(3) Budgeting	1	2	3	4	5
(4) Hiring and firing staff	1	2	3	4	5
(5) Equipment purchases	1	2	3	4	5

SECTION SIX: SATISFACTION

XI. Overall, how satisfied are you in your job? Circle the appropriate response.

Very Dissat-isfied 1	Dissat-isfied 2	Neither Dissatisfied Nor Satisfied 3	Satisfied 4	Very Satisfied 5

Thank you very much for your help and cooperation in answering this questionnaire! Please return in the addressed postage paid envelope provided.

Measure # 13: Primary Care Assessment Survey (PCAS)

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 14: National Survey of Children with Special Health Care Needs (CSHCN)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

The Child and Adolescent Health Measurement Initiative (CAHMI)
P: (503) 494-1930
cahmi@ohsu.edu

Copyright Details:

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National Survey of Children with Special Health Care Needs (NS-CSHCN), 2005 - 2006

Guide to Topics & Questions Asked

SECTION 1: NIS/SLAITS Eligibility and Screeners

1. How many children between the ages of 12 months and 3 years old are living or staying in your household? **(S_NUMB)**
2. How many people less than 18 years old live in this household? **(S_UNDR18)**

SECTION 2: Initial Household Screening for Special Health Care Needs

The parent or guardian who is the most familiar with the health and health care situations of the children in the household answers the following questions for each child in the household under 18 years old:

1. Child's age **(C2Q01B)**
2. Child's sex **(C2Q03)**
3. CSHCN Screener questions:
   - Does child currently need or use medicine prescribed by a doctor, other than vitamins? **(CSHCN1)**
     - Is [his/her] need for prescription medicine because of ANY medical, behavioral or other health condition? **(CSHCN1_A)**
     - Is this a condition that has lasted or is expected to last 12 months or longer? **(CSHCN1_B)**
   - Does child need or use more medical care, mental health or educational services than is usual for most children of the same age? **(CSHCN2)**
     - Is [his/her] need for medical care, mental health, or educational services because of ANY medical, behavioral or other health condition? **(CSHCN2_A)**
     - Is this a condition that has lasted or is expected to last 12 months or longer? **(CSHCN2_B)**
   - Is child limited or prevented in any way in [his/her] ability to do the things most children of the same age can do? **(CSHCN3)**
     - Is [his/her]'s limitation in abilities because of ANY medical, behavioral or other health condition? **(CSHCN3_A)**
     - Is this a condition that has lasted or is expected to last 12 months or longer? **(CSHCN3_B)**
   - Does child need or get special therapy such as physical, occupational, or speech therapy? **(CSHCN4)**
     - Is [his/her] need for special therapy because of ANY medical, behavioral or other health condition? **(CSHCN4_A)**
     - Is this a condition that has lasted or is expected to last 12 months or longer? **(CSHCN4_B)**
   - Does child have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling? **(CSHCN5)**
     - Has [his/her]'s emotional, developmental, or behavioral problem lasted or expected to last for 12 months or longer? **(CSHCN5_A)**
4. Child's race/ethnicity **(CW10Q01, CW10Q02)**

SECTION 2: Initial Household Screening for Special Health Care Needs *(continued)*

Respondent Information

5. What is the highest level of school that anyone in the household has completed or the highest degree anyone in the household has received? **(CW10Q04)**

6. What is the primary language spoken in your home? **(C2Q05)**

7. Respondent's relationship to the [CHILD'S NAME] **(C2Q04)**

SECTION 3: Child Health and Functional Status

1. How often does [CHILD'S NAME]'s health condition affect [his/her] ability to do age-appropriate things? (**C3Q02)**

   - If so, how much limitation does child experience? **(C3Q03)**

2. Do [CHILD'S NAME]'s health care needs change all the time, change once in awhile or are usually stable? **(C3Q11)**

3. Without glasses or contact lenses, would you say [he/she] experiences any difficulty seeing? **(S3Q01)**

   - Does [CHILD'S NAME] wear glasses or contact lenses? **(S3Q01A)**

   - Does [CHILD'S NAME] have any difficulty seeing even when wearing glasses or contact lenses? **(S3Q01B)**

4. Without hearing aids, would you say [he/she] experiences any difficulty hearing? **(S3Q02)**

   - Does [CHILD'S NAME] use a hearing aid? **(S3Q02A)**

   - Does [CHILD'S NAME] have any difficulty hearing even when using a hearing aid? **(S3Q02B)**

5. Would you say [he/she] experiences any difficulty with any of the following:

   - Breathing or other respiratory problems, such as wheezing or shortness of breath? **(S3Q03)**
   - Swallowing, digesting food, or metabolism? **(S3Q04)**
   - Blood circulation? **(S3Q05)**
   - Repeated or chronic physical pain, including headaches? **(S3Q06)**

6. Compared to other children [his/her] age, would you say he/she experiences any difficulty with any of the following:

   - Taking care of [himself/herself], for example, doing things like eating, dressing and bathing? **(S3Q07)**
   - Coordination or moving around **(S3Q08)**
   - Using [his/her] hands **(S3Q09)**
   - Learning, understanding, or paying attention? **(S3Q10)**
   - Speaking, communicating, or being understood? **(S3Q11)**
   - With feeling anxious or depressed? **(S3Q12)**
   - With behavior problems, such as acting-out, fighting, bullying, or arguing? **(S3Q13)**
   - Making and keeping friends? **(S3Q14)**

SECTION 3: Child Health and Functional Status *(continued)*

7. Overall, how would you rate the severity of the difficulties caused by [CHILD'S NAME]'s health problems? **(C3Q10)**

8. You reported that [CHILD'S NAME] does not experience any difficulty in any of the areas just mentioned. In your opinion, would you say this is because [CHILD'S NAME]'s health problems are being treated and are under control? **(S3Q15)**

9. To the best of your knowledge, does [CHILD'S NAME] currently have any of the following conditions?
   - Asthma? **(S3Q16)**
   - Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD)? **(S3Q17)**
   - Autism or Autism Spectrum Disorder (ASD)? **(S3Q18)**
   - Down Syndrome? **(S3Q19)**
   - Mental retardation or developmental delay? **(S3Q20)**
   - Depression, anxiety, an eating disorder, or other emotional problems? **(S3Q21)**
   - Diabetes? **(S3Q22)**
     - Does [CHILD'S NAME] use insulin? **(S3Q22A)**
   - A heart problem, including congenital heart disease? **(S3Q23)**
   - Blood problems such as anemia or sickle cell disease? Please do not include Sickle Cell Trait. **(S3Q25)**
   - Cystic Fibrosis? **(S3Q26)**
   - Cerebral Palsy? **(S3Q27)**
   - Muscular Dystrophy? **(S3Q28)**
   - Epilepsy or other seizure disorder? **(S3Q29)**
   - Migraine or frequent headaches? **(S3Q30)**
   - Arthritis or other joint problems? **(S3Q32)**
   - Allergies? **(S3Q31)**
     - Food allergies? **(S3Q31_A)**

10. If school age, number of school days missed during the past 12 months because of illness or injury? **(C3Q14)**

11. During the past 12 months, how many times did [CHILD'S NAME] visit a hospital emergency room? **(C6Q00)**

12. During the past 12 months, how many times did [CHILD'S NAME] visit a doctor or other health care provider? **(C6Q01)**

SECTION 4: Access to Care — Use of Services and Unmet Needs

1. Is there a place [CHILD'S NAME] usually goes when [he/she] is sick or you need advice about [his/her] health? **(C4Q0A)**
   - What kind of place? **(C4Q0B INDEX –** *asked only for children with a usual source of care***)**
   - Is there a place that [CHILD'S NAME] usually goes when [he/she] needs routine preventive care, such as a physical exam or a well-child check-up? **(C4Q0D-** *asked only for children without a usual source of care***)**

2. Is the [place selected in C4Q0B] that (CHILD'S NAME) goes to when [he/she] is sick the same place [CHILD's NAME] usually goes for routine preventive care? **(C4Q01 –** *asked only for a YES response to C4Q0D***)**
   - What kind of place does [CHILD'S NAME] go for routine preventive care? **(C4Q02 INDEX –** *asked only for a NO response to C4Q01***)**

SECTION 4: Access to Care — Use of Services and Unmet Needs *(continued)*

3. Do you have one or more persons you think of as [CHILD'S NAME]'s personal doctor or nurse? **(C4Q02A)**
   - Who is this person? (**C4Q02B INDEX –** *asked only for children who have a personal doctor or nurse*)

4. In past 12 months, have you delayed or gone without health care for [CHILD'S NAME]? **(C4Q03)**
   - Why did you delay or not get health care for [CHILD'S NAME]? **(C4Q04_A – C4Q04_L INDEX–** *asked only for respondents who delayed health care*)

5. In the past 12 months was there any time when [CHILD'S NAME] needed the following services:

	Needed Services?	Received all needed care?	Reasons for not receiving care?	Received any care?
• Routine preventive care:	(C4Q05_X01)	(C4Q05X01A)	(C4Q0501B)	(C4Q05X01C)
• Specialty care:	(C4Q05_X02)	(C4Q05X02A)	(C4Q0502B)	(C4Q05X02C)
• Preventive dental care:	(C4Q05_X031)	(C4Q05X031A)	(C4Q05031B)	(C4Q05X031C)
• Other dental care:	(C4Q05_X032)	(C4Q05X032A)	(C4Q05032B)	(C4Q05X032C)
• Prescription medications:	(C4Q05_X04)	(C4Q05X04A)	(C4Q0504B)	(C4Q05X04C)
• Physical, Occupational, or Speech Therapy:	(C4Q05_X05)	(C4Q05X05A)	(C4Q0505B)	(C4Q05X05C)
• Mental health care or counseling:	(C4Q05_X06)	(C4Q05X06A)	(C4Q0506B)	(C4Q05X06C)
• Substance abuse treatment or counseling:	(C4Q05_X07)	(C4Q05X07A)	(C4Q0507B)	(C4Q05X07C)
• Home health care:	C4Q05_X08)	(C4Q05X08A)	---	(C4Q05X08C)
• Eyeglasses or vision care:	C4Q05_X09)	(C4Q05X09A)	---	(C4Q05X09C)
• Hearing aids or hearing care:	(C4Q05_X10)	(C4Q05X10A)	---	(C4Q05X10C)
• Mobility aids or devices:	(C4Q05_X11)	(C4Q05X11A)	---	(C4Q05X11C)
• Communication aids or devices:	(C4Q05_X12)	(C4Q05X12A)	---	(C4Q05X12C)
• Medical supplies:	(C4Q05_X13)	(C4Q05X13A)	---	(C4Q05X13C)
• Durable medical equipment:	(C4Q05_X14)	(C4Q05X14A)	---	(C4Q05X14C)

6. In the past 12 months was there any time when you or other family members needed the following services:

	Family needed services?	Family received all needed care?	Reasons for not receiving care?	Family received any care?
• Respite care	(C4Q06_X01)	(C4Q06X01A)	(C4Q0601B)	(C4Q06X01C)
• Genetic counseling	(C4Q06_X02)	(C4Q06X02A)	(C4Q0602B)	(C4Q06X02C)
• Mental health care or counseling	(C4Q06_X03)	(C4Q06X03A)	(C4Q0603B)	(C4Q06X03C)

7. Does [CHILD'S NAME] receive Early Intervention Services? **(C3Q12 –** *children ages 2 and younger only*)

8. Does [CHILD'S NAME] receive Special Education Services? **(C3Q13 –** *children ages 2 and older only*)

SECTION 5: Care Coordination

1. During the past 12 months, did [CHILD'S NAME] need a referral to see any doctors or receive any services? **(C5Q11)**
   - Was getting referrals a big problem, a small problem, or not a problem? **(C4Q07 –** *only children with YES to needing a referral***)**
2. Does anyone help you arrange or coordinate [CHILD'S NAME]'s care among the different doctors or services that he/she uses? **(C5Q12 –** *only children who responded YES to two or more of questions C4Q05X01A-C4Q05X14A, C4Q05X01C-C4Q05X14C, C5Q01, C3Q12, or C3Q13***)**
   - Does a doctor or someone in a doctor's office provide this help arranging or coordinating [CHILD'S NAME]'s care? **(C5Q13 –** *only children with YES to help coordinating care***)**
   - Who does provide help arranging or coordinating [CHILD'S NAME]'s care? **(C5Q14 INDEX –** *only children with NO to help coordinating care***)**
3. Is there anyone else who helps arrange or coordinate [CHILD'S NAME]'s care? **(C5Q15)**
   - Who is this person? **(C5Q16 INDEX –** *only children with YES to others helping to coordinate care***)**
4. During the past 12 months, have you felt that you could have used extra help arranging or coordinating [CHILD'S NAME]'s care among these different health care providers or services? **(C5Q17)**
   - How often did you get as much help as you wanted with arranging or coordinating [CHILD'S NAME]'s care? **(C5Q09 –** *only children with YES to extra help with coordinating care***)**
5. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [CHILD'S NAME]'s doctors and other health care providers? **(C5Q10)**
6. Do [CHILD'S NAME]'s doctors or other health care providers need to communicate with [his/her] school, early intervention program, child care providers, vocational education or rehabilitation program? **(C5Q05)**
   - Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication? ***(C5Q06 –*** *only children with YES to doctors communicating with school***)**

SECTION 6A: Family Centered Care

In the past 12 months:

1. How often did [CHILD'S NAME]'s doctors and other health care providers spend enough time with [him/her]? **(C6Q02 -** *asked of respondents whose children visited a doctor or health care provider in the last 12 months***)**
2. How often did [CHILD'S NAME]'s doctors and other health care providers listen carefully to you? **(C6Q03-** *asked of respondents whose children visited a doctor or health care provider in the last 12 months***)**
3. How often were [CHILD'S NAME]'s doctors and other health care providers sensitive to your family's values and customs? **(C6Q04-** *asked of respondents whose children visited a doctor or health care provider in the last 12 months***)**
4. How often did you get the specific information you needed from [CHILD'S NAME]'s doctors and other health care providers? **(C6Q05-** *asked of respondents whose children visited a doctor or health care provider in the last 12 months***)**
5. How often did [CHILD'S NAME]'s doctors and other health care providers help you feel like a partner in his or her care? **(C6Q06-** *asked of respondents whose children visited a doctor or health care provider in the last 12 months***)**
6. During the past 12 months, did you [or CHILD'S NAME] need an interpreter to help speak with [his/her] doctors or other health care providers? **(S5Q13** *– based on respondent's answer to C2Q05 which asks about the household's primary spoken language***)**
   - When you [or CHILD'S NAME] needed an interpreter, how often were you able to get someone other than a family member to help you speak with [his/her] doctors or other health care providers? **(S5Q13A** *– asked of respondents who needed an interpreter to help speak with the doctor***)**

SECTION 6B: Transition Issues

7. Do any of [CHILD'S NAME]'s doctors or other health care providers treat only children? **(C6Q07** *– ages 12-17 only***)**
   - Have they talked with you about having [CHILD'S NAME] eventually see doctors or other health care providers who treat adults? **(C6Q0A_B** *– only children with YES to providers only treating children***)**
   - Would a discussion about doctors who treat adults have been helpful to you? **(C6Q0A_C** *– only children with NO to providers only treating children***)**
8. Have [CHILD'S NAME]'s doctors or other health care providers talked with you or [CHILD'S NAME] about [his/her] health care needs as he/she becomes an adult? **(C6Q0A***– ages 12-17 only***)**
   - Would a discussion about [CHILD'S NAME]'s health care needs have been helpful? **(C6Q0A_D***– only children with NO to providers talking about transition to adulthood***)**
9. Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as [CHILD'S NAME] becomes an adult? **(C6Q0A_E***– ages 12-17 only***)**
   - Would a discussion about health insurance have been helpful to you? **(C6Q0A_F***– only children with NO to a discussion about health insurance coverage***)**
10. How often do [CHILD'S NAME]'s doctors or other health care providers encourage [him/her] to take responsibility for [his/her] health care needs? **(C6Q08** *– children ages 5-17 only***)**

SECTION 6C: Ease of Service Use

11. Thinking about [CHILD'S NAME]'s health needs and all the services that he/she needs, have you had any difficulties trying to use these services during the past 12 months? **(C6Q0D)**
    - Did you have any difficulties for any of the following reasons **(C6Q0E INDEX –** *only children with difficulties trying to use services***)**
12. Thinking about [CHILD'S NAME]'s health needs and the services he/she receives, how satisfied or dissatisfied are you with those services? **(C6Q0C)**

SECTION 7: Health Insurance

This section asks an extensive series of questions about [CHILD'S NAME]'s health insurance status and source(s) of coverage. Responses to these questions are considered confidential, but are used to determine if a child is insured at the time of the survey. The following variables are released in the public use dataset.

- How many CSHCN were without insurance at the time of the survey?
- How many CSHCN were without insurance at some point in the past year?
- How many CSHCN have private or public insurance?

SECTION 8: Adequacy of Health Care Coverage

1. Does [CHILD'S NAME]'s health insurance offer benefits or cover services that meet [his/her] needs? **(C8Q01_A –** *only children with current insurance***)**
2. Are the costs not covered by [CHILD'S NAME]'s health insurance reasonable? **(C8Q01_B–** *only children with current insurance***)**
3. Does [CHILD'S NAME] health insurance company allow [him/her] to see the health care providers he/she needs? **(C8Q01_C–** *only children with current insurance***)**

SECTION 9: Impact on the Family

1. During the past 12 months, would you say that the family paid more than $500, $250-%500, less than $250 or nothing for [CHILD'S NAME]'s medical care? **(C9Q01)**

   - Would you say that the family paid more than $5,000, $1,000 to $5,000, or less than $1,000 for [CHILD'S NAME]'s medical care? **(C9Q01A** *– asked only for children paying more than $500 for medical care***)**

2. Do you or other family members provide health care at home for [CHILD'S NAME]? **(C9Q02)**

   - How many hours per week? **(C9Q03 –** *asked only for children whose family members provide health care at home***)**

3. How many hours a week do you or other family members spend arranging or coordinating [CHILD'S NAME]'s care? **(C9Q04)**

4. Have [CHILD'S NAME]'s health condition(s) caused financial problems for your family? **(C9Q05)**

5. Have you or other family members stopped working because of [CHILD'S NAME]'s health condition(s)? **(C9Q10)**

6. Have you or other family members cut down on the hours you work because of [CHILD'S NAME]'s health? **(C9Q06)**

7. Have you needed additional income to cover [CHILD'S NAME]'s medical expenses? **(C9Q07)**

SECTION 10: Family Composition

NOTE: *Responses to the other questions in this section are considered confidential, and are used to create a single derived variable on family composition available with the public use data set.*

- Please tell me how many people live in this household, including all children and anyone who normally lives here even if they are not here now, like someone who is away traveling or in the hospital **(C11Q01_A)**

SECTION 11: Household Income

1. Does [CHILD'S NAME] receive Supplemental Security Income (SSI)? **(C11Q12)**

   - Is this for a disability? **(C11Q13 –** *asked for children who received supplemental security income***)**

2. At any time during the last 12 months, did anyone in the household receive any cash assistance from a state or county welfare program? **(C11Q11 –** *asked only for households below the 200% poverty level***)**

SECTION 11A: Telephone Line and Household Information

The questions in this section ask about zip code and number of telephone lines in the household. This information is used to mathematically weight the sample so it more accurately represents all families, including those without telephones. The questions in this section were not released due to confidentiality.

Measure # 15: Head and Neck Cancer Integrated Care Indicators

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 16a: Medical Home Index – Long Version (MHI-LV)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

W. Carl Cooley, MD
Chief Medical Office, Crotched Mountain Foundation
Medical Director, Center for Medical Home Improvement
Adjunct Professor of Pediatrics, Dartmouth Medical School
cooley@cmf.org
P: (603) 228-8111

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

The Medical Home Index (MHI) is a validated self-assessment and classification tool designed to translate the broad indicators defining the medical home (accessible, family-centered, comprehensive, coordinated, etc.) into observable, tangible behaviors and processes of care within any office setting. It is a way of measuring and quantifying the "medical homeness" of a primary care practice. The MHI is based on the premise that "medical home" is an evolutionary process rather than a fully realized status for most practices. The MHI measures a practice's progress in this developmental process.

The MHI defines, describes, and quantifies activities related to the organization and delivery of primary care for all children and youth. A population of vulnerable children and youth, including those with special health care needs, benefit greatly from having a high quality medical home. Medical Home represents *the* standard of excellence for pediatric primary care, this means the primary care practice is ready and willing to provide well, acute and chronic care for all children and youth, including those affected by special health care needs or who hold other risks for compromised health and wellness.

You will be asked to rank the level (1-4) of your practice in six domains: organizational capacity, chronic condition management, care coordination, community outreach, data management and quality improvement/change. Most practices may not function at many of the higher levels (Levels 3 and 4). However these levels represent the kinds of services and supports which families report that they need from their medical home. A frank assessment of your current practice will best characterize your medical home baseline, and will help to identify needed improvement supports.

A companion survey to the Medical Home Index, the Medical Home Family Index (MHFI), is intended for use with a cohort of practice families (particularly those who have children/youth affected by a chronic health condition). The MHFI is to be completed by families whose children receive care from a practice with whom their child has been seen for over a year. The Medical Home Family Index provides the practice team with a valuable parent/consumer perspective on the overall experience of care.

Guidelines

CMHI tools are made available to you on our web site www.medicalhomeimprovement.org . When using these tools we request that you:

1) Inform CMHI in writing of your intent for use (e-mail is fine).
2) Make every effort to gain family feedback using the MHFI (or other tool). We believe that "medical homeness" cannot be fully measured without an analysis of the family perspective.
3) We would also appreciate you sharing data with us (in a confidential fashion). Most programs have done this by sending copies of the Medical Home Index and MHFI (with all practice and personal identifiers removed), or by simply sharing aggregate data.

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

Clinic Contact Information

Date

Clinic Name:

Street Address:

City: State: Zip Code:

Phone: Fax

Who took the lead in completing this form?

Who should we contact at your clinic if we have questions about your responses, or if responses are missing/incomplete?

Name (if different than the person who completed this form):

Title/Position/Role:

Best phone number to reach contact if different than above:

Contact E-mail:

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

Describe your practice type/model _____ Number of clinicians: MD's ____ ARNPs ____ PA's ____ Other ____

Is there a care coordinator working at your practice who supports children, youth and families? ○ Yes ○ No

What is the estimated number of children that your practice cares for? _____ What is your patient panel size? _____

Can you estimate the percentage (total should = 100%) of children you care for who have:

1) ____ % Public insurance only (Medicaid/Medicare)
2) ____ % Private & Medicaid/Medicare
3) ____ % Self/No pay
4) ____ % Private insurance only
5) ____ % Other

How familiar/knowledgeable are you about the concept of a medical home as defined by the American Academy of Pediatrics?

1) ☐ No knowledge of the concepts
2) ☐ Some knowledge/not applied
3) ☐ Knowledgeable/concept sometimes applied in practice
4) ☐ Knowledgeable/concepts regularly applied in practice

How familiar/knowledgeable are you about the elements of family-centered care as defined by the US Maternal and Child Health Bureau?

1) ☐ No knowledge of the concepts
2) ☐ Some knowledge/not applied
3) ☐ Knowledgeable/concept sometimes applied in practice
4) ☐ Knowledgeable/concepts regularly applied in practice

(Note: Any italicized words are defined in the glossary on page 15)

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

INSTRUCTIONS:

This instrument is organized under six domains:

1) Organizational Capacity 2) Chronic Condition Management 3) Care Coordination

4) Community Outreach 5) Data Management 6) Quality Improvement

Each domain has anywhere from 2 -7 themes, these themes are represented with progressively comprehensive care processes and are expressed as a continuum from Level 1 through Level 4. For each theme please do the following:

First: Read each theme across its progressive continuum from Levels 1 to Level 4.

Second: Select the LEVEL (1, 2, 3 or 4) which best describes how your *practice* currently provides care for patients with chronic health condition (some activity within that level).

Third: When you have selected your Level, please indicate whether *practice* performance within that level is: ***"PARTIAL"*** ***"COMPLETE"*** (all activity within that level).

For the example below, **"Domain 1: Organizational Capacity; Theme 1. 1 "The Mission..."** the score for the *practice* is: **"Level 3", "PARTIAL".**

EXAMPLE

Domain 1: Organizational Capacity: For CSHCN and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#1.1 The Mission of the Practice	*Primary care providers (PCPs)* at the *practice* have individual ways of delivering care to children with special health care needs CSHCN; their own education, experience and interests drive care quality.	*Approaches to the care of CSHCN* at the *practice* are child rather than *family-centered*; office needs drive the implementation of care (e.g. the process of carrying out care).	**The practice uses a *family-centered* approach to care (see page15), they assess *CSHCN* and the needs of their families in accordance with its mission; feedback is solicited from families and influences office policies (e.g. the way things are done).**	In addition to Level 3, a parent/ ***practice*** "advisory group" promotes ***family-centered*** strategies, practices and policies (e.g. enhanced communication methods or systematic inquiry of family concerns/priorities); a written, visible mission statement reflects practice commitment to quality care for *CSHCN* and their families.
	☐ PARTIAL ☐ COMPLETE	☐ PARTIAL ☐ COMPLETE	☒ PARTIAL ☐ COMPLETE	☐ PARTIAL ☐ COMPLETE

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Domain 1: Organizational Capacity: For CSHCN and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#1.1 The Mission of the Practice	*Primary care providers (PCPs)* at the *practice* have individual ways of delivering care to children with special health care needs (CSHCN); their own education, experience and interests drive care quality. ○ Partial ○ Complete	Approaches to the care of *CSHCN* at the *practice* are child rather than *family-centered*; office needs drive the implementation of care (e.g. the process of carrying out care). ○ Partial ○ Complete	The practice uses a *family-centered* approach to care (see page15), they assess *CSHCN* and the needs of their families in accordance with its mission; feedback is solicited from families and influences office policies (e.g. the way things are done). ○ Partial ○ Complete	In addition to Level 3, a parent/*practice* "advisory group" promotes *family-centered* strategies, practices and policies (e.g. enhanced communication methods or systematic inquiry of family concerns/priorities); a written,visible mission statement reflects practice commitment to quality care for CSHCN and their families. ○ Partial ○ Complete
#1.2 Communi-cation/ Access	Communication between the family and the *PCP* occurs as a result of family inquiry; *PCP* contacts with the family are for test result delivery or planned medical follow-up. ○ Partial ○ Complete	In addition to Level 1, standardized office communication methods are identified to the family by the practice (e.g. call-in hours, phone triage for questions, or provider call back hours). ○ Partial ○ Complete	Practice and family communicate at agreed upon intervals and both agree on "best time and way to contact me"; individual needs prompt weekend or other special appointments. ○ Partial ○ Complete	In addition to Level 3, office activities encourage individual requests for flexible access; access and communication preferences are documented in the care plan and used by other practice staff (e.g. fax, e-mail or web messages, home, school or residential care visits). ○ Partial ○ Complete
#1.3 Access to the Medical Record ***Requires both MD & key non-MD staff person's perspective.***	A policy of access to medical records is not routinely discussed with families; records are provided only upon request. ○ Partial ○ Complete	In addition to Level 1, it is established among staff that families can review their child's record (but this fact is not explicitly shared with families). ○ Partial ○ Complete	All families are informed that they have access to their child's record; staff facilitates access within 24-48 hours. ○ Partial ○ Complete	In addition to Level 3, practice orientation materials include information on record access; staff locate space for families to read their child's record and make themselves available to answer questions. ○ Partial ○ Complete

Instructions: A) **Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).**
B) **Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).**

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Domain 1: Organizational Capacity (continued): For *CSHCN* and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#1.4 Office Environment *Requires both MD & key non-MD staff person's perspective.*	Special needs concerning physical access and other visit accommodations are considered at the time of the appointment and are met if possible. ○ Partial ○ Complete	Assessments are made during the visit of children with special health care needs and the needs of their families; any physical access & other visit accommodation needs are addressed at the visit and are documented for future encounters. ○ Partial ○ Complete	In addition to Level 2, staff ask about any new or pre-existing physical and social needs when scheduling appoint ments; chart documentation is updated and staff are informed/ prepared ahead of time ensuring continuity of care. ○ Partial ○ Complete	In addition to Level 3, key staff identify children scheduled each day with special health care needs, prepare for their visit and assess and document new needs at the visit; an office care coordinator prepares both office staff and the office environment for the visit; s/he advocates for changes (office/environmental) as needed. ○ Partial ○ Complete
#1.5 Family Feedback *Requires both MD & key non-MD staff person's perspective.*	Family feedback to the *practice* occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with practice staff. ○ Partial ○ Complete	Feedback from families of *CSHCN* is elicited sporadically by individual practice providers or by a suggestion box; this feedback is shared informally with other providers and staff. ○ Partial ○ Complete	Feedback from families of *CSHCN* regarding their perception of care is gathered through systematic methods (e.g. surveys, focus groups, or interviews); there is a process for staff to review this feedback and to begin problem solving. ○ Partial ○ Complete	In addition to Level 3, an advisory process is in place with families of *CSHCN* which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g. childcare or parent stipends). ○ Partial ○ Complete
#1.6 Cultural Competence	The *primary care provider* (*PCP*) attempts to overcome obstacles of language, literacy, or personal preferences on a case by case basis when confronted with barriers to care. ○ Partial ○ Complete	In addition to Level 1, resources and information are available for families of the most common diverse cultural backgrounds; others are assisted individually through efforts to obtain translators or to access information from outside sources. ○ Partial ○ Complete	In addition to Level 2, materials are available and appropriate for non-English speaking families, those with limited literacy; these materials are appropriate to the developmental level of the child/young adult. ○ Partial ○ Complete	In addition to Level 3, family assessments include pertinent cultural information, particularly about health beliefs; this information is incorporated into care plans; the *practice* uses these encounters to assess patient & community cultural needs. ○ Partial ○ Complete

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Domain 1: Organizational Capacity (continued): For *CSHCN* and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#1.7 Staff Education *Requires both MD & key non-MD staff person's perspective.*	For all staff, an orientation to internal office practices, procedures and policies is provided. ○ Partial ○ Complete	In addition to Level 1, the practice supports (paid time/ tuition support) continuing education for all staff in the care of CSHCN (children with special health care needs). ○ Partial ○ Complete	In addition to Level 2, educational information on community-based resources for CSHCN, including diagnosis specific resource information, is available for all staff. ○ Partial ○ Complete	In addition to Level 3, families of CSHCN are integrated into office staff orientations and educational opportunities as teachers or "family faculty"; support for families to take this role is provided. ○ Partial ○ Complete

Domain 2: Chronic Condition Management (*CCM*): For *CSHCN* and Their Families

THEME:	*Level 1*	*Level 2* (in addition to level 1)	*Level 3* (in addition to level 2)	*Level 4* (in addition to level 2)
#2.1 Identification of Children in the Practice with Special Health Care Needs	Children with special health care needs (*CSHCN)* can be counted informally (e.g. by memory or from recent acute encounter); comprehensive identification can be done through individual chart review only. ○ Partial ○ Complete	Lists of children with special health care needs are extracted electronically by diagnostic code. ○ Partial ○ Complete	A CSHCN list is generated by applying a definition (see pg. 15), the list is used to enhance care +/or define practice activities (e.g. to flag charts and computer databases for special attention or identify the population and its subgroups). ○ Partial ○ Complete	In addition to Level 3, diagnostic codes for CSHCN are documented, problem lists are current, and complexity levels are assigned to each child; this information creates an accessible practice database. ○ Partial ○ Complete
#2.2 Care Continuity	Visits occur with the child's own primary care provider (PCP) as a result of acute problems or well child schedules; the family determines follow up. ○ Partial ○ Complete	Non-acute visits occur with families and their PCP to address chronic condition care; the PCP determines appropriate visit intervals; follow-up includes communication of tasks to staff and of lab and medical test results to the family. ○ Partial ○ Complete	The team (including *PCP,* family, and staff) develops a plan of care for *CSHCN* which details visit schedules and communication strategies; home, school and community concerns are addressed in this plan. Practice back up/cross coverage providers are informed by these plans. ○ Partial ○ Complete	In addition to Level 3, the practice/teams use condition protocols; they include goals, services, interventions and referral contacts. A designated care coordinator uses these tools and other standardized office processes which support children and families. ○ Partial ○ Complete

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Domain 2: Chronic Condition Management (continued): For *CSHCN* and Their Families				
THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#2.3 Continuity Across Settings	Communication among the *PCP*, specialists, therapists, and school happens as needs arise for *CSHCN*. ○ Partial ○ Complete	A PCP makes requests and/or responds to requests from agencies or schools on behalf of CSHCN (e.g. specific needs for accommodations, medical orders or approval of plans, or for a particular classroom placement); all communication is documented. ○ Partial ○ Complete	Systematic practice activities foster communication among the practice, family, and external providers such as specialists, schools, and other community professionals for CSHCN; these methods are documented and may include information exchange forms or ad hoc meetings with external providers. ○ Partial ○ Complete	In addition to Level 3, a method is used to convene the family and key professionals on behalf of children with more complex health concerns; specific issues are brought to this group and they all share and use a written plan of care. ○ Partial ○ Complete
#2.4 Cooperative Management Between Primary Care Provider (*PCP*) and Specialist	Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their primary care provider (PCP). ○ Partial ○ Complete	In addition to Level 1, specialty referrals use phone, written and/or electronic communications; the PCP waits for or relies upon the specialists to communicate back their recommendations. ○ Partial ○ Complete	The PCP and family set goals for referrals and communicate these to specialists; together they clarify comanagement roles among family, PCP and specialists and determine how specialty feedback to the family and PCP is expressed, used, and shared. ○ Partial ○ Complete	In addition to Level 3, the family has the option of using the *practice* in a strong coordinating role; parents as partners with the *practice* manage their child's care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their child's care). ○ Partial ○ Complete

Instructions: A) **Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).**
B) **Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).**

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Domain 2: Chronic Condition Management (continued): For *CSHCN* and Their Families				
THEME:	*Level 1*	*Level 2* (in addition to level 1)	*Level 3* (in addition to level 2)	*Level 4* (in addition to level 3)
# 2.5.1* Supporting the Transition to Adulthood ** transition measure revised August, 2006.*	Pediatric and adolescent primary care providers (PCPs) adhere to defined health maintenance schedules for youth with special health care needs in their practice. ○ Partial ○ Complete	Pediatric and adolescent PCPs offer age appropriate anticipatory guidance for specific youth & families related to their chronic condition, self-care, nutrition, fitness, sexuality, and other health behavior information. ○ Partial ○ Complete	Pediatric and adolescent PCPs support youth & family to manage their health using a transition time line & developmental approach; they assess needs & offer culturally effective guidance related to: • health & wellness • education & vocational planning • guardianship and legal & financial issues • community supports & recreation When youth transition from pediatrician to adult provider: **Pediatricians** help to identify an adult PCP and sub-specialists and offer ongoing consultation to youth, family and providers during the transition process. **Adult Providers** offer an initial "welcome" visit and a review of transition goals. ○ Partial ○ Complete	Progressively from age 12, youth, family and PCP develop a written transition plan within the care plan; it is made available to families and all involved providers. Youth and families receive coordination support to link their health and transition plans with other relevant adolescent and adult providers/services/ agencies (e.g. sub-specialists, educational, financial, insurance, housing, recreation employment and legal assistance). ○ Partial ○ Complete
#2.6 Family Support *Requires both MD & key non-MD staff person's perspective.*	Families are responsible for carrying out recommendations made to them by their ***PCP*** when they specifically ask for family support or help. ○ Partial ○ Complete	The ***practice*** responds to clinical needs; broader social and family needs are addressed and referrals to support services facilitated. ○ Partial ○ Complete	The ***practice*** actively takes into account the overall family impact when a child has a chronic health condition by considering all family members in care; when families request it, staff will assist them to set up family support connections. ○ Partial ○ Complete	In addition to Level 3, the ***practice*** sponsors family support activities (e.g. skills building for parents of CSHCN on how to become a supporting parent); they have current knowledge of community or state support organizations and connect parents to them. ○ Partial ○ Complete

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Domain 3: Care Coordination For *CSHCN* and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#3.1 Care Coordination /Role Definition	The family coordinates care without specific support; they integrate office recommendations into their child's care. ○ Partial ○ Complete	The *primary care provider* (*PCP*) or a staff member engages in care support activities as needed; involvement with the family is variable. ○ Partial ○ Complete	Care coordination activities are based upon ongoing assessments of child and family needs; the practice partners with the family (and older child) to accomplish care coordination goals. ○ Partial ○ Complete	Practice staff offer a set of care coordination activities (*see page 16), their level of involvement fluctuates according to family needs/wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring. ○ Partial ○ Complete
#3.2 Family Involvement	The PCP makes medical recommendations and defines care coordination needs, the family carries these out. ○ Partial ○ Complete	Families (and their older *CSHCN* are regularly asked what care supports they need; treatment decisions are made jointly with the *PCP*. ○ Partial ○ Complete	In addition to Level 2, families (and older CSHCN) are given the option of centralizing care coordination activities at and in partnership with the *practice*. ○ Partial ○ Complete	In addition to Level 3, children & families contribute to a description of care coordination activities; a care coordinator specifically develops and implements this practice capacity which is evaluated by families and designated supervisors. ○ Partial ○ Complete
#3.3 Child and Family Edu-cation *Requires both MD & key non-MD staff person's perspective.*	Generic and specific reading materials and brochures are available from the *practice* upon request. ○ Partial ○ Complete	Basic information relevant to *CSHCN* is offered in one on one interactions with children and families; these encounters use supportive written information with resource information. ○ Partial ○ Complete	General information regarding having a child with special needs, and diagnosis specific information, is offered by the practice in a standardized manner; education anticipates potential issues and problems and refers families to other educational resources. ○ Partial ○ Complete	In addition to Level 3, diverse materials and teaching methods are used to address individual learning styles & needs; education is broad in scope and learning outcomes are examined. ○ Partial ○ Complete

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Domain 3: Care Coordination (continued): For *CSHCN* and Their Families:

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#3.4 Assessment of Needs/ Plans of Care	Presentation of CSHCN with acute problems determines how needs are addressed. ○ Partial ○ Complete	PCPs identify specific needs of CSHCN; follow-up tasks are arranged for, or are assigned to families &/or available staff. ○ Partial ○ Complete	The child with special needs, family, and PCP review current child health status and anticipated problems or needs; they create/ revise action plans and allocate responsibilities at least 2 times per year or at individualized intervals. ○ Partial ○ Complete	In addition to Level 3, the *PCP*/staff and families create a written plan of care that is monitored at every visit; the office care coordinator is available to the child and family to implement, update and evaluate the care plan. ○ Partial ○ Complete
#3.5 Resource Information and Referrals ***Requires both MD & key non-MD staff person's perspective.***	Information about resource needs and insurance coverage is gathered during regular family visit intakes; the *practice* addresses immediate family information and resource needs. ○ Partial ○ Complete	Using a listing of community, state, and national resources which cover physical, developmental, social and financial needs the *practice* responds to family requests for information; the family seeks out additional information & may share back lessons learned. ○ Partial ○ Complete	Significant office knowledge about family and medical resources and insurance options is available; assessment of family needs leads to supported use of resources and information to solve specific problems. ○ Partial ○ Complete	In addition to Level 3, practice staff work with families helping solve resource problems; a designated care coordinator provides follow up, researches additional information, seeks and provides feedback and assists with the family to integrate new information into the care plan. ○ Partial ○ Complete
#3.6 Advocacy	The *PCP* suggests that the family find support services & resources outside of the *practice* when specific needs arise (e.g. diagnosis specific support groups, disability rights organizations, or Parent Support and Information Centers). ○ Partial ○ Complete	All families of CSHCN are routinely provided with basic information about Parent to Parent groups, family support, and advocacy resources during scheduled practice visits. ○ Partial ○ Complete	The practice team identifies resources to the family for support and advocacy, facilitates the connections, and advocates on a family's behalf to solve specific problems pertinent to CSHCNs. ○ Partial ○ Complete	In addition to Level 3, this team advocates on behalf of all CSHCN and their families as a population and helps to create opportunities for community forums, discussions or support groups which address specific concerns. ○ Partial ○ Complete

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Domain 4: Community Outreach: For *CSHCN* and Their Families

THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#4.1 Community Assessment of Needs for *CSHCN*	*Primary care provider (PCP)* awareness of the population of children with special health care needs *CSHCN* in their community is directly related to the number of children for whom the provider cares. ○ Partial ○ Complete	The practice learns about issues and needs related to *CSHCN*s from key community inform-ants; providers blend this input with their own personal observations to make an informal and personal assessment of the needs of *CSHCN* in their community. ○ Partial ○ Complete	In addition to Level 2, providers raise their own questions regarding the population of *CSHCN* in their practice community(ies); they seek pertinent data and information from families and local/state sources and use data to inform practice care activities. ○ Partial ○ Complete	In addition to Level 3, at least one clinical practice provider participates in a community-based public health need assessment about *CSHCN*, integrates results into practice policies, and shares conclusions about population needs with community & state agencies. ○ Partial ○ Complete
#4.2 Community Outreach to Agencies and Schools.	When the family, school or agency request interactions with the *primary care provider* (*PCP*) on behalf of a child's community needs, the provider responds, thereby establishing the practice as a resource. ○ Partial ○ Complete	In addition to Level 1, when a community agency or school requests technical assistance or education from the practice about *CSHCN*, the practice communicates, collaborates, and educates based upon availability and interest. ○ Partial ○ Complete	The practice initiates outreach to community agencies and schools that directly serve *CSHCN* (e.g. through representation on one or more advisory boards or committees); they advocate for improved community services and inter-organizational collaboration & communication. ○ Partial ○ Complete	In addition to Level 3, the *practice* identifies needs of *CSHCN* & their families; they work with families to sponsor activities that raise community awareness to resource and support needs (e.g. specialized home care, respite care recreation opportunities, or improving home/school/ provider communication). ○ Partial ○ Complete

Instructions: **A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).**
B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).

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Domain 5: Data Management: For *CSHCN* and Their Families				
THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#5.1 Electronic Data Support	*Primary care providers (PCPs)* retrieve information/data by individual chart review; electronic data are available and retrievable from payer sources only. ○ Partial ○ Complete	Electronic recording of data is limited to billing & scheduling; data are retrieved according to diagnostic code in relation to billing and scheduling; these data are used to identify specific patient groupings. ○ Partial ○ Complete	An electronic data system includes identifiers and utilization data about children with special health care needs CSHCN; these data are used for monitoring, tracking, and for indicating levels of care complexity. ○ Partial ○ Complete	In addition to Level 3, an electronic data system is used to support the documentation of need, monitoring of clinical care, care plan and related coordination and the determination of outcomes (e.g. clinical, functional, satisfaction and cost outcomes). ○ Partial ○ Complete
#5.2 Data Retrieval Capacity	*PCP* retrieves patient data from paper records in response to outside agency requirements (e.g. *quality* standards, special projects, or *practice* improvements). ○ Partial ○ Complete	The *practice* retrieves data from paper records and electronic billing and scheduling for the support of significant office changes (e.g. staffing, or allocation of resources). ○ Partial ○ Complete	Data are retrieved from electronic records to identify and quantify populations and to track selected health indicators & outcomes. ○ Partial ○ Complete	In addition to Level 3, electronic data are produced and used to drive practice improvements & to measure *quality* against benchmarks; (those producing and using data practice confidentiality). ○ Partial ○ Complete

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Domain 6: Quality Improvement/Change: For *CSHCN* and Their Families				
THEME:	*Level 1*	*Level 2*	*Level 3*	*Level 4*
#6.1 Quality Standards (structures)	Quality standards for children with special health care needs (*CSHCN)* are imposed upon the *practice* by internal or external organizations. ○ Partial ○ Complete	In addition to Level 1, an individual staff member participates on a committee for improving processes of care at the *practice* for *CSHCN*. This person communicates and promotes improvement goals to the whole practice. ○ Partial ○ Complete	The *practice* has its own systematic quality improvement mechanism for *CSHCN*; regular provider and staff meetings are used for input and discussions on how to improve care and treatment for this population. ○ Partial ○ Complete	In addition to Level 3, the *practice* actively utilizes quality improvement (QI) processes; staff and parents of *CSHCN* are supported to participate in these QI activities; resulting quality standards are integrated into the operations of the *practice*. ○ Partial ○ Complete
#6.2 Quality Activities (processes)	*Primary care providers (PCPs)* have completed courses or have had an adequate orientation to continuous quality improvement methods. ○ Partial ○ Complete	Corporate owners, administrators or payers identify *practice* deficits and set goals for improvements; *practice* providers and staff are identified to fix problems with limited participation in the process. ○ Partial ○ Complete	Periodic formal, and informal quality improvement activities gather staff input about *practice* improvement ideas and opportunities for CSHCN; efforts are made toward related changes and improvements for this population. ○ Partial ○ Complete	In addition to Level 3, the *practice* systematically learns about *CSHCN* & draws upon family input; together the *practice* and families design and implement office changes that address needs and gaps; they then study their outcomes and act accordingly. ○ Partial ○ Complete

Please make certain you have chosen a Level (1-4).
Also indicate whether your *practice* performance within that level is "partial" (some activity within that level) or "complete" (all activity within the level). Thank You

Instructions: **A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).**
B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

Definitions of Core Concepts (Words in *italics* throughout the document are defined below.)

Children with Special Health Care Needs (CSHCN):
Children with special health care needs are defined by the US Maternal and Child Health Bureau as those who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (USDHHS, MCHB, 1997).

Medical Home:
A medical home is a community-based primary care setting which provides and coordinates high *quality*, planned, patient/family-centered: health promotion (acute, preventive) and *chronic condition management* (© CMHI, 2006).

Family-Centered Care (US Maternal and Child Health Bureau, 2004):
Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

Glossary of Terms

Practice-Based Care Coordination

Care and services performed in partnership with the family and providers by health professionals to:

1) Establish family-centered community-based Medical Homes for ***CSHCN*** and their families.
   - -Make assessments and monitor child and family needs
   - -Participate in parent/professional practice improvement activities

2) Facilitate timely access to the ***Primary Care Provider*** (***PCP***), services and resources
   - -Offer supportive services including counseling, education and listening
   - -Facilitate communication among PCP, family and others

3) Build bridges among families and health, education and social services; promotes continuity of care
   - -Develop, monitor, update and follow-up with care planning and care plans
   - -Organize wrap around teams with families; support meeting recommendations and follow-up

4) Supply/provide access to referrals, information and education for families across systems.
   - -Coordinate inter-organizationally
   - -Advocate with and for the family (e.g. to school, day care, or health care settings)

5) Maximize effective, efficient, and innovative use of existing resources
   - -Find, coordinate and promote effective and efficient use of current resources
   - -Monitor outcomes for child, family and practice

Chronic Condition Management (CCM):

CCM acknowledges that children and their families may require more than the usual well child, preventive care, and acute illness interventions. CCM involves explicit changes in the roles of providers and office staff aimed at improving:

1) Access to needed services
2) Communication with specialists, schools, and other resources, and
3) Outcomes for patients, families, *practices*, employers and payers.

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The Medical Home Index: Pediatric

Measuring the Organization and Delivery of Pediatric Primary Care for *All* Children, Youth and Families

GLOSSARY OF TERMS ★ (continued)

Quality:
Quality is best determined or judged by those who need or who use the services being offered. *Quality* in the medical home is best achieved when one learns what children with special health care needs and their families require for care and what they need for support. Health care teams in partnership with families then work together in ways which enhance the capacity of the family and the practice to meet these needs. Responsive care is designed in ways which incorporate family needs and suggestions. Those making practice improvements must hold a commitment to doing what needs to be done and agree to accomplish these goals in essential partnerships with families.

Office Policies:
Definite courses of action adopted for expediency; "the way we do things"; these are clearly articulated to and understood by all who work in the office environment.

Practice:
The place, providers, and staff where the PCP offers pediatric care

Primary Care Provider - (PCP):
Physician or pediatric nurse practitioner who is considered the main provider of health care for the child

United States Maternal and Child Health Bureau - (USMCHB):
A division of Health Resources Services Administration

Requires both MD and key non-MD staff person's perspective - you will see this declaration before select themes; CMHI has determined that these questions require the input of both MD and non MD staff to best capture practice activity.

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Summary/Notes

Notes, comments and questions:

Comments:

Questions:

Confusing themes:

What do you want to be asked that this measurement tool does not address?

What would you like us to know about the quality of care that you provide?

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Measure # 16b: Medical Home Index – Short Version (MHI-SV)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

W. Carl Cooley, MD
Chief Medical Office, Crotched Mountain Foundation
Medical Director, Center for Medical Home Improvement
Adjunct Professor of Pediatrics, Dartmouth Medical School
cooley@cmf.org
P: (603) 228-8111

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The Medical Home Index - Short Version:

Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

The Medical Home Index - Short Version (MHI-SV) represents ten indicators which have been derived from the Center for Medical Home Improvement's (CMHI) original Medical Home Index (MHI). This short version can be used as an interval measurement in conjunction with the original MHI ***or*** it can be used as a quick "report card" or snapshot of practice quality. CMHI recommends the use of the full MHI for practice improvement purposes but offers this short version for interval or periodic measurement and/or when it is not feasible to use the full MHI.

The Medical Home Index is a nationally validated self-assessment tool designed to quantify the "medical homeness" of a primary care practice. The MHI contains twenty-five indicators which detail excellent, pro-active, comprehensive pediatric primary care. It functions both as a quality improvement tool and as a self education medium relevant to the medical home.

The Medical Home Index: Short Version (MHI-SV) is a brief representation of the more complete measurement tool. It scores a practice on a continuum of care across three levels:

- Level 1 is good, responsive pediatric primary care.
- Level 2 is pro-active pediatric primary care (in addition to Level 1)
- Level 3 illustrates pediatric primary care at the most comprehensive levels (it is in addition to Levels 1 and 2).

As the reporter for your entire practice and in response to each of the ten indicators - please score your medical home at: Level 1, Level 2 "partial", Level 2 "complete", Level 3 "partial", or Level 3 "complete".

Both the full 25-item Medical Home Index and this 10-item Medical Home Index – Short Version can be downloaded from the CMHI website at www.medicalhomeimprovement.org.

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Medical Home Index – Short Version (MHI-SV)

	Level 1	***Level 2*** (in addition to level 1)	***Level 3*** (in addition to level 2)
# 1 Family Feedback ***Requires both MD & key non-MD staff person's perspective.*** *(# 1.5 MHI-Full Version)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	Feedback from families of ***CSHCN*** regarding their perception of care is gathered through systematic methods (e.g. surveys, focus groups, or interviews); there is a process for staff to review this feedback and to begin problem solving. ❒ **PARTIAL** ❒ **COMPLETE**	An advisory process is in place with families of ***CSHCN*** which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g. childcare or parent stipends). ❒ **PARTIAL** ❒ **COMPLETE**
# 2 Cultural Competence *(# 1.6 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	Materials are available and appropriate for non-English speaking families, those with limited literacy; these materials are appropriate to the developmental level of the child/young adult. ❒ **PARTIAL** ❒ **COMPLETE**	Family assessments include pertinent cultural information, particularly about health beliefs; this information is incorporated into care plans; the ***practice*** uses these encounters to assess patient & community cultural needs. ❒ **PARTIAL** ❒ **COMPLETE**
#3 Identification of Children in the Practice with Special Health Care Needs *(# 2.1 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	A ***CSHCN*** list is generated by applying a definition (see pg. 6), the list is used to enhance care +/or define ***practice*** activities (e.g. to flag charts and computer databases for special attention or identify the population and its subgroups). ❒ **PARTIAL** ❒ **COMPLETE**	Diagnostic codes for ***CSHCN*** are documented, problem lists are current, and complexity levels are assigned to each child; this information creates an accessible ***practice*** database. ❒ **PARTIAL** ❒ **COMPLETE**

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Medical Home Index – Short Version (MHI-SV)

	Level 1	***Level 2*** (in addition to level 1)	***Level 3*** (in addition to level 2)
#4 **Care Continuity** *(# 2.2 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	The team (including ***PCP***, family, and staff) develops a plan of care for ***CSHCN*** which details visit schedules and communication strategies; home, school and community concerns are addressed in this plan. Practice back up/cross coverage providers are informed by these plans. ❒ **PARTIAL** ❒ **COMPLETE**	The ***practice***/teams use condition protocols; they include goals, services, interventions and referral contacts. A designated care coordinator uses these tools and other standardized office processes which support children and families. ❒ **PARTIAL** ❒ **COMPLETE**
#5 **Cooperative Management Between Primary Care Provider (PCP) and Specialist** *(# 2.4 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	The ***PCP*** and family set goals for referrals and communicate these to specialists; together they clarify co-management roles among family, ***PCP*** and specialists and determine how specialty feedback to the family and ***PCP*** is expressed, used, and shared. ❒ **PARTIAL** ❒ **COMPLETE**	The family has the option of using the ***practice*** in a strong coordinating role; parents as partners with the ***practice*** manage their child's care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their child's care). ❒ **PARTIAL** ❒ **COMPLETE**

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Medical Home Index – Short Version (MHI-SV)

	Level 1	***Level 2*** (in addition to level 1)	***Level 3*** (in addition to level 2)
#6 Supporting the Transition to Adulthood *(# 2.5.1 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	Pediatric and adolescent PCPs support youth & family to manage their health using a transition timeline & developmental approach; they assess needs & offer culturally effective guidance related to: • health & wellness • education & vocational planning • guardianship and legal & financial issues • community supports & recreation When youth transition from pediatrician to adult provider: **Pediatricians** help to identify an adult PCP and sub-specialists and offer ongoing consultation to youth, family and providers during the transition process. **Adult Providers** offer an initial "welcome" visit and a review of transition goals. ❒ **PARTIAL** ❒ **COMPLETE**	Progressively from age 12, youth, family and PCP develop a written transition plan within the care plan; it is made available to families and all involved providers. Youth and families receive coordination support to link their health and transition plans with other relevant adolescent and adult providers/services/agencies (e.g. sub-specialists, educational, financial, insurance, housing, recreation employment and legal assistance). ❒ **PARTIAL** ❒ **COMPLETE**
#7 Care Coordination /Role Definition *(# 3.1 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	Care coordination activities are based upon ongoing assessments of child and family needs; the ***practice*** partners with the family (and older child) to accomplish care coordination goals. ❒ **PARTIAL** ❒ **COMPLETE**	Practice staff offer a set of care coordination activities, their level of involvement fluctuates according to family needs/wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring. ❒ **PARTIAL** ❒ **COMPLETE**

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Medical Home Index – Short Version (MHI-SV)

	Level 1	***Level 2*** (in addition to level 1)	***Level 3*** (in addition to level 2)
#8 Assessment of Needs/ Plans of Care *(# 3.4 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	The child with special needs, family, and ***PCP*** review current child health status and anticipated problems or needs; they create/revise action plans and allocate responsibilities at least 2 times per year or at individualized intervals. ❒ **PARTIAL** ❒ **COMPLETE**	The ***PCP***/staff and families create a written plan of care that is monitored at every visit; the office care coordinator is available to the child and family to implement, update and evaluate the care plan. ❒ **PARTIAL** ❒ **COMPLETE**
#9 Community Assessment of Needs for CSHCN *(# 4.1 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	Providers raise their own questions regarding the population of **CSHCN** in their practice community(ies); they seek pertinent data and information from families and local/state sources and use data to inform practice care activities. ❒ **PARTIAL** ❒ **COMPLETE**	At least one clinical practice provider participates in a community-based public health need assessment about **CSHCN**, integrates results into practice policies, and shares conclusions about population needs with community & state agencies. ❒ **PARTIAL** ❒ **COMPLETE**
#10 Quality Standards (structures) *(# 6.1 MHI-FV)*	Pediatric primary care without the elements detailed in levels 2 and 3. ❒ **Level 1**	The ***practice*** has its own systematic quality improvement mechanism for ***CSHCN***; regular provider and staff meetings are used for input and discussions on how to improve care and treatment for this population. ❒ **PARTIAL** ❒ **COMPLETE**	The ***practice*** actively utilizes quality improvement (QI) processes; staff and parents of ***CSHCN*** are supported to participate in these QI activities; resulting quality standards are integrated into the operations of the ***practice***. ❒ **PARTIAL** ❒ **COMPLETE**

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The Medical Home Index - Short Version:

Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

DEFINITIONS OF CORE CONCEPTS (Words in italics throughout the document are defined below.)

Children with Special Health Care Needs (CSHCN):

Children with special health care needs are defined by the ***US Maternal and Child Health Bureau*** as those who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (USDHHS, MCHB, 1997).

Medical Home:

A medical home is a community-based primary care setting which provides and coordinates high quality, planned, family-centered health promotion and chronic condition management. According to the American Academy of Pediatrics (AAP) "medical home" is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

Family-Centered Care (US Maternal and Child Health Bureau, 2004):

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

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The Medical Home Index – Short Version:

Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

GLOSSARY OF TERMS (continued)

Care Coordination Activities:

Care and services performed in partnership with the family and providers by health professionals to:

1) Establish family-centered community-based **"Medical Homes"** for ***CSHCN*** and their families.
   - -Make assessments and monitor child and family needs
   - -Participate in parent/professional practice improvement activities

2) Facilitate timely access to the ***Primary Care Provider*** (***PCP***), services and resources
   - -Offer supportive services including counseling, education and listening
   - -Facilitate communication among PCP, family and others

3) Build bridges among families and health, education and social services; promotes continuity of care
   - -Develop, monitor, update and follow-up with care planning and care plans
   - -Organize wrap around teams with families; support meeting recommendations and follow-up

4) Supply/provide access to referrals, information and education for families across systems.
   - -Coordinate inter-organizationally
   - -Advocate with and for the family (e.g. to school, daycare, or health care settings)

5) Maximize effective, efficient, and innovative use of existing resources
   - -Find, coordinate and promote effective and efficient use of current resources
   - -Monitor outcomes for child, family and practice

Chronic Condition Management (CCM):

CCM acknowledges that children and their families may require more than the usual well child, preventive care, and acute illness interventions.

CCM involves explicit changes in the roles of providers and office staff aimed at improving:

1) Access to needed services
2) Communication with specialists, schools, and other resources, and
3) Outcomes for children and families.

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The Medical Home Index – Short Version:

Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

GLOSSARY OF TERMS* (continued)

Quality:

Quality is best determined or judged by those who need or who use the services being offered. Quality in the medical home is best achieved when one learns what children with special health care needs and their families require for care and what they need for support. Health care teams in partnership with families then work together in ways which enhance the capacity of the family and the practice to meet these needs. Responsive care is designed in ways which incorporate family needs and suggestions. Those making practice improvements must hold a commitment to doing what needs to be done and agree to accomplish these goals in essential partnerships with families.

Office Policies

Definite courses of action adopted for expediency; "the way we do things"; these are clearly articulated to and understood by all who work in the office environment.

Practice:

The place, providers, and staff where the PCP offers pediatric care

Primary Care Provider - (PCP):

Physician or pediatric nurse practitioner who is considered the main provider of health care for the child

United States Maternal and Child Health Bureau - (USMCHB):

A division of Health Resources Services Administration

Requires both MD and key non-MD staff person's perspective - you will see this declaration before select themes; the project has found that these questions require the input of both MD and non MD staff to best capture practice activity.

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Measure # 16c: Medical Home Family Index and Survey (MHFIS)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

W. Carl Cooley, MD
Chief Medical Office, Crotched Mountain Foundation
Medical Director, Center for Medical Home Improvement
Adjunct Professor of Pediatrics, Dartmouth Medical School
cooley@cmf.org
P: (603) 228-8111

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The Medical Home
Family Index and Survey

CMHI
Center for
Medical Home
Improvement

Crotched Mountain Foundation
18 Low Ave, STE 1
Concord, NH 03301
603-228-8111 (Fax) 603-228-8344

Center for
Medical Home
Improvement

THE MEDICAL HOME *FAMILY* INDEX:

Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

A community-based primary care "medical home" is a health care practice in your community that is completely responsive to you and your child's needs. This is especially so when your child has a chronic health condition or disability. A group at the Hood Center for Children and Families at Children's Hospital at Dartmouth Hitchcock Medical Center (New Hampshire) has been asked to create a Medical Home Index to find out about the medical "homeness" of a health care practice or office.

Your child's primary care provider fills out The Medical Home Index; this set of questions looks at the care activities that make the medical home "come alive" in practice. Health care providers will rate the care that they offer to children with special health care needs and their families. They will comment on how they partner with families in their children's care and provide care coordination and other needed supports.

No questionnaire truly captures the medical "homeness" of a practice unless information is gathered from families. You are being asked to fill out this Medical Home Family Index and to report on the services and supports that your child actually receives. The Medical Home Family Index uses twenty-five questions to capture the family perspective, please try to answer each question to the best of your ability. Thank-you for your willingness to complete this set of questions and for your thoughtful comments written at its end.

Please turn to the next page . . .

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THE MEDICAL HOME *FAMILY* INDEX:

Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

The following questions refer to the care that your child receives from his/her pediatrician or primary care provider (PCP) and the staff who work in their office. Next to each question circle the response that best describes your experience of care for your child.

1. Through this practice/office I can get the health care that my child needs when we need it (including after office hours, on weekends and holidays).	Never	Sometimes	Often	Always
2. When I call the office: (please answer for a, b, c, and d):				
a) Staff know who we are	Never	Sometimes	Often	Always
b) Staff respect our needs and requests	Never	Sometimes	Often	Always
c) Staff remember any special needs or supports that we have asked for	Never	Sometimes	Often	Always
d) We are asked if there are any new needs requiring attention	Never	Sometimes	Often	Always
3. My primary care provider (PCP) uses helpful ways to communicate (e.g. explaining terms clearly, helping us prepare for visits, e-mail, or encouraging our questions):				
a) With me	Never	Sometimes	Often	Always
b) With my child (If (b) does not apply to your child ✔here ___)	Never	Sometimes	Often	Always
4. My PCP asks me to share with him/her my knowledge and expertise as the parent or caregiver of a child with special health care needs (CSHCN).	Never	Sometimes	Often	Always
5. I am asked by our PCP how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	Never	Sometimes	Often	Always
6. My PCP listens to my concerns and questions?	Never	Sometimes	Often	Always
7. Planning of care for my child includes: (please answer for a, b, c and d):				
a) The writing down of key information (e.g. recommendations, treatments, phone #)	Never	Sometimes	Often	Always
b) Setting short team goals (e.g. for the next three months)	Never	Sometimes	Often	Always
c) Setting long term goals (e.g. for the next year or more)	Never	Sometimes	Often	Always
d) Thorough follow-up with plans created	Never	Sometimes	Often	Always
8. My primary care provider and staff work with our family to create a written care plan for my child. (If your answer is "never", then skip to Question # 11)	Never	Sometimes	Often	Always

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9. I receive a copy of my child's care plan with all updates and changes.	Never	Sometimes	Often	Always
10. My primary care provider (PCP) and his/her office staff (please answer a, b and c):				
a) Use and follow through with care plans they have created	Never	Sometimes	Often	Always
b) Use a care plan to help follow my child's progress	Never	Sometimes	Often	Always
c) Review and update the care plan with me regularly	Never	Sometimes	Often	Always
11. My PCP has a staff person(s) or a "care coordinator" who will:				
a) Help me with difficult referrals, payment issues, and follow-up activities	Never	Sometimes	Often	Always
b) Help to find needed services (e.g. transportation, durable equipment or home care)	Never	Sometimes	Often	Always
c) Make sure that the planning of care meets my child and my families needs	Never	Sometimes	Often	Always
d) Help each person involved in my child's care to communicate with each other (with my consent).	Never	Sometimes	Often	Always
12. When or if I ask for it, our PCP or office staff help me to:				
a) Explain my child's needs to other health professionals	Never	Sometimes	Often	Always
b) Get my child's school, early care providers or others to understand his/her condition (If (b) does not apply to your child ✔here ___)	Never	Sometimes	Often	Always
13. Someone at the office is available to review my child's medical record with me when or if I ask to see it.	Yes		No	
14. Office providers or staff who are involved with my child's care know about their condition, history, and our concerns and priorities.	Yes		No	
15. My PCP or his/her office staff sponsor activities to support my family (e.g. support groups, parent skill building or how to support other parents).	Yes		No	
16. Office staff help me to connect with family support organizations and informational resources in our community and state.	Yes		No	
17. My PCP is a strong advocate for the rights and services important to children with special health care needs and their families.	Yes		No	
18. My PCP assists me in finding adult health care services for my child. (Check here if due to your child's age this does not apply _____).	Yes		No	

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19. My primary care provider (PCP) and office staff organize and attend team meetings about my child's plan of care that include us and outside providers (when needed).	Yes		No	
20. My PCP and office staff organize and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	Yes		No	
21. I have seen changes made at the office as a result of my suggestions or those made by other families.	Yes		N	
22. I know the practice has conducted surveys, focus groups, or discussions with families (in the last two years) to determine if they are satisfied with their children's care.	Yes		No	
23. From my experience, I believe that my PCP and the staff at his/her office have a commitment to provide the quality care and family supports that we need.	Yes		No	
24. The behavior which best demonstrates the needed care and compassion I need from my child's PCP is _____ (write in here).	Comments:			
25. The frequency that I observe and experience this behavior (in #24) is?	Never	Sometimes	Often	Always

Would you please go back over this Family Index to check for unanswered questions; try to answer them to the best of your ability.

Please write down:

The name of the practice where you go for your child's care: _____

The name of your child's primary care provider: _____

The length of time your child has been cared for by this practice? _____ Your child's age: _____

Your name, address, & social security #: _____

Address: _____ SS# _____

(Optional) What is the racial/ethnic background with which you most closely identify?

❒ White, Non-Hispanic ❒ African American ❒ Hispanic ❒ Native American/American Indian/Alaskan Native ❒ Asian ❒ Other (specify)

May we have your permission to contact you further about this project? ❒ Yes ❒ No

Other comments you would like to make? (Feel free to use the other side) _____ *Thank You for Sharing Your Experiences*

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Center for Medical Home Improvement
Family/Caregiver Survey

Today's date: __/__/__

My child is a (1) ____ Boy (2) ____Girl

Child's date of birth (or age in total months):_____

Each of the following questions (unless otherwise stated) refers to right now or in the past 12 months. When questions do not apply to your family or child, circle or write NA (not applicable).

In your opinion what is your child's **(most)** primary medical condition? (**Circle only one**)

1) Arthritis	10) Deafness/trouble hearing	22) Muscular dystrophy
2) Asthma	11) Depression	23) Obesity
3) Attention deficit/hyperactivity	12) Diabetes	24) Recurrent urinary tract infection
4) Autism/pervasive development disorder	13) Down syndrome	25) Seizure disorder
5) Blindness/trouble seeing	14) Eating disorder	26) Severe allergies
6) Cerebral palsy	15) Heart disease or heart defect	27) Severe scoliosis
7) Chronic ear infection	16) Hemophilia	28) Sickle cell disease
8) Cleft lip/palate	17) HIV/AIDS	29) Spina bifida
9) Cystic fibrosis	18) Permanent deformity of arms/legs	30) Other (specify below)
	19) Kidney disease	_____
	20) Leukemia/Cancer	_____
	21) Mental retardation	_____

Select from the list above (1-29) any additional conditions that your child has, write the number of the condition (s) on the lines below. If your child's additional condition(s) are not on the list, please also write it/them on the lines below.

a._____ d._____

b._____ e._____

c._____ f._____

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Caring for Your Child

The next five questions ask about your child's health needs and whether your child has a health condition. A **health condition** can be physical, mental or behavioral. **Health conditions** may affect a child's development, daily function or need for services.

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ❒ Yes → Go to Question 1a
   - ❒ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 1b
   - ❒ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ❒ Yes → Go to Question 2a
   - ❒ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 2b
   - ❒ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ❒ Yes → Go to Question 3a
   - ❒ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 3b
   - ❒ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

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4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ❒ Yes → Go to Question 4a
   - ❒ No → Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 4b
   - ❒ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ❒ Yes → Go to Question 5a
   - ❒ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

6. In general, would you say your child's **health** is: (Circle one)

   (1) Excellent (2) Good (3) Fair (4) Poor

7. Is there a place that your child usually goes to when he/she is sick or you need advice about his/her health?

   1) Yes 2) No 3) There is more than one place

8. A personal doctor or nurse is the health provider who knows your child best. Do you have one person that you think of as your child's personal doctor or nurse?

   1) Yes 2) No 3) Don't know

9. How **difficult** is it to take care of your child's chronic health condition(s) or disability?

   (1) Not at all difficult (3) Some what difficult
   (2) A little difficult (4) Very difficult

10. During the last 3 months, how often have you worried about your child's **health**? (Circle One)

    (1) None of the time (4) Most of the time
    (2) A little of the time (5) All of the time
    (3) Some of the time

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11. During the last 3 months, how often have you worried about the impact of your child's chronic health condition or disability **upon his or her siblings**?

(1) None of the time
(2) A little of the time
(3) Some of the time
(4) Most of the time
(5) All of the time
(6) Does not apply to your family

12. Overall, how would you rank the **severity** of your child's condition or problem?
Please pick a number from "0" to "10" where "0" is the mildest severity, "10" is the most severe.

0 1 2 3 4 5 6 7 8 9 10

Mildest severity **Most severe**

13. Which of the following statements best describes your child's health care needs?

1) Child's health care needs change all the time
2) Child's health care needs change only once in awhile
3) Child's health care needs are usually stable
4) None of the above
5) Don't know

14. How would you measure the level of stress experienced over the last year as a result of caring for your child?
Please pick a number from "0" to "10" where "0" represents very low stress and "10" is for extremely high stress.

0 1 2 3 4 5 6 7 8 9 10

Very low stress **Extremely high stress**

15. Does your child's doctor or office staff help to alleviate this stress (e.g. with services, supports, or referrals to other resources)?

1) Always
2) Often
3) Sometimes
4) Never

16. During the last month, how often have your emotions (such as feeling depressed or anxious) interfered with your work, social activities, or daily routine?

1) None of the time
2) A little of the time
3) Some of the time
4) Most of the time
5) All of the time

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17. During the past 12 months (1 year ago today) how many days did your child miss school because of their chronic health condition or disability?

Write in the number of days _____ (a typical school year has ~185)

17a. Also indicate:

(1) None (no days absent)
(2) Did not go to school
(3) Home schooled
(4) Don't know

18. Do you have any of the following specific concerns for your child?
(Circle the number under the response that best describes your concern):

	Never	**Seldom**	**Sometimes**	**Often**	**Always**	**NA**
18a. Growth and development	1	2	3	4	5	6
18b. Ability to learn	1	2	3	4	5	6
18c. Participation in activities of his/her age group	1	2	3	4	5	6
18d. Ability to make healthy choices (e.g. activity, rest, diet, medicines)	1	2	3	4	5	6
18e. Self esteem/emotional well being	1	2	3	4	5	6
18f The future	1	2	3	4	5	6

NA (not applicable)

19. How would you estimate the current overall **severity** of your child's special health care needs?
(1) Minimal
(2) Mild
(3) Moderate
(4) Severe

20. Are things the same from day to day with your child, or is it hard to know what to expect?
(1) Pretty much the same day to day
(2) Occasional surprises
(3) Lots of unexpected changes
(4) Very unpredictable one day to the next

Using the Health Care System

21. How satisfied are you with the care coordination provided outside of the family that you receive for your child?
(1) Very satisfied
(2) Somewhat satisfied
(3) Dissatisfied
(4) Very dissatisfied
(5) NA (not applicable)

22. During the past year, how many times was your child seen by your child's primary care provider?
(1) None at all
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times
(5) NA (not applicable)

23. During the past year, how many times was your child seen by a specialist/specialty clinic?
(1) None
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times

24. During the past year, how many times did your child require care in the emergency room?
(1) None
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times

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25. During the past year, how many separate times did your child have to stay in the hospital overnight?
    (1) None at all
    (2) 1 - 3 times
    (3) 4 - 7 times
    (4) 8 - 10 times
    (5) More than 10 times

26. In the past 3 months, how many days have you or anyone in your family had to **stay home from work** because of your child's chronic health condition(s) or disability?
    (1) None
    (2) 1 – 5 work days
    (3) 6 - 16 work days
    (4) 16 or more work days
    (5) No one is employed

Family Care Coordination

Parents of children with chronic health conditions often do a variety of activities to coordinate care for their child. Some parents are new at this, others have been coordinating their child's care for years. Listed below are some of the care activities parents often do. Please read each activity and **circle** the response that best describes you and your family.

	Always	**Often**	**Some-Times**	**Rarely**	**Never**	**NA**
27. Involving my child in regular recreational activities in the community.	1	2	3	4	5	6
28. Finding the help I need to coordinate services for my child.	1	2	3	4	5	6
29. Finding other parents to talk to who have children with similar conditions.	1	2	3	4	5	6
30. Describing how this medical condition affects my child's growth and development.	1	2	3	4	5	6
31. Taking action to correct poor care and services my child receives.	1	2	3	4	5	6
32. (*If school age or older*) Getting my child to take an active role as possible in health discussions and in decision making.	1	2	3	4	5	6
33. Communicating my concerns about my child's health needs to most professionals.	1	2	3	4	5	6
34. Getting medical professionals to give us information that we can understand.	1	2	3	4	5	6

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Practice Satisfaction: How would you rate the practice for each of the following qualities?

Please circle one number on each line.	**Excellent**	**Very Good**	**Good**	**Fair**	**Poor**	**NA**
35. The length of time waiting at the office.	1	2	3	4	5	6
36. Clear directions for who to contact or where to go for aspects of your child's condition when they are not ill.	1	2	3	4	5	6
37. Provider(s) and staff have regular contact with your child's school staff.	1	2	3	4	5	6

38. How many **additional** children live in your home?
1) none 2)one 3) two 4) three 5) four 6) five 7) six or more

39. Has anyone in your family been **unable to work** outside the home due to your child's health condition or disability?
1) yes 2) no

40. What do you or your child currently need that you are ***not*** receiving?

_____

_____

Family Information	**Yes**	**No**	**Don't Know**
41. Do you have health insurance for yourself?	1	2	DK
42. Do you have health insurance for your child?	1	2	DK
43. Do you have Medicaid for your child?	1	2	DK
44. Do you have supplemental security income (SSI)?	1	2	DK
45. Do you receive any other assistance from the state (e.g. special medical services, children with special needs)?	1	2	DK
46. Do you have regular out of pocket health expenses (over $50/month or over $600/year) to care for your child's health condition or disability (not including insurance deductibles or co-payments)?	1	2	DK

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47. Are out of pocket expenses related mostly to (circle all that apply):

1. Equipment
2. Supplies
3. Medications
4) Family support
5) Counseling
6) Respite care
7) Other _____ (write in)

Please use the space below to express your thoughts about this survey or any of the areas it has caused you to think about.

_____

_____

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_____

Thank you for your help and time in completing this survey

CMHI (Center for Medical Home Improvement), Crotched Mountain Foundation
18 Low Ave, STE 1, Concord NH 03301
603-228-8111 (Fax) 603-228-8344
www.medicalhomeimprovement.org

(Questions 1-5 are from the FACCT – Foundation for Accountability CAMHI/ Chronic Condition Screener)

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Measure # 17a: Primary Care Assessment Tool – Child Expanded Edition (PCAT-CE)

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Measure # 17b Primary Care Assessment Tool – Adult Expanded Edition (PCAT-AE)

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Measure # 17c: Primary Care Assessment Tool – Facility Expanded Edition (PCAT-FE)

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Measure # 17d: Primary Care Assessment Tool – Provider Expanded Edition (PCAT-PE)

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Measure # 18: Physician-Pharmacist Collaboration Instrument (PPCI)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Alan J. Zillich, Pharm.
Associate Professor
College of Pharmacy
Purdue University

Purdue Pharmacy Practice Office
W7555 Myers Bldg.
Wishard Health Services
1001 W. 10th Street
Indianapolis, IN 46202-2879, USA
azillich@purdue.edu

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Additional Notes:

- The measure instrument does not have individual items numbered. When referencing specific items within the *Atlas* measure profile, all instrument items were numbered consecutively in the order of appearance.

Physician / Pharmacist Collaboration Survey

Consider your working relationship with the pharmacist(s) at XXXXXXXXX. Think, in general, about the interactions you've had with this pharmacist(s) over time. Please indicate your agreement with each of the following statements by using the scale listed below. Please circle the number that represents your agreement with the item.

SCALE: **1-Very Strongly Disagree 2-Strongly Disagree 3-Disagree 4-Neutral 5-Agree 6-Strongly Agree 7-Very Strongly Agree**

In providing patient care, I need this pharmacist as much as this pharmacist needs me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
The pharmacist is credible.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
My interactions with this pharmacist are characterized by open communication of both parties.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I can count on this pharmacist to do what he/she says.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist depends on me as much as I depend on him/her.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist and I are mutually dependent on each other in caring for patients.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist and I negotiate to come to agreement on our activities in managing drug therapy.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I will work with this pharmacist to overcome disagreements on his/her role in managing drug therapy.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I intend to keep working together with this pharmacist.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I trust this pharmacists' drug expertise.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Communication between this pharmacist and myself is two-way.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist has spent time trying to learn how he/she can help you provide better care.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist has provided information to you about a specific patient.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This pharmacist has showed an interest in helping you improve your practice.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Physician / Pharmacist Collaboration Survey

Consider your working relationship with the physician at XXXXXXXXX. Think, in general, about the interactions you've had with this physician over time. Please indicate your agreement with each of the following statements by using the scale listed below. Please circle the number that represents your agreement with the item.

SCALE: **1-Very Strongly Disagree 2-Strongly Disagree 3-Disagree 4-Neutral 5-Agree 6-Strongly Agree 7-Very Strongly Agree**

For our practices, I need this physician as much as this physician needs me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This physician is credible.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
My interactions with this physician are characterized by open communication by both parties.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I can count on this physician to do what he/she says.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This physician depends on me as much as I depend on them.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This physician and I are mutually dependent on each other in caring for patients.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This physician and I negotiate to come to an agreement on my activities in managing drug therapy.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
This physician will work with me to overcome disagreements on my role in managing drug therapy.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I intend to keep working together with this physician.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I trust this physician.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Communication between this physician and myself is two-way.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I spend time trying to learn how I can help this physician provide better care.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I provide information to this physician about specific patients.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
I try to understand the needs of this physician's practice.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Measure # 19: Patient Centered Medical Home Survey of the Structural Capabilities of Primary Care Practice Sites

Contact Information:

- Contact information unavailable.

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Measure # 20: Family Medicine Medication Use Processes Matrix (MUPM)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Dr. Barbara Farrell, BScPhm, PharmD, FCSHP
Clinical and Research Coordinator, Pharmacy Department
Bruyère Continuing Care, Scientist, Élizabeth Bruyère Research Institute
43 Bruyère Street
Ottawa, Ontario, Canada KIN 5C8
P: +1 (613) 562-0500 x. 1315; F: +1 (613) 562-4266
bfarrell@bruyere.org

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Additional Notes:

- The measure instrument does not have individual items numbered. When referencing specific items within the *Atlas* measure profile, all instrument items were numbered consecutively in the order of appearance.

Family Practice Medication Use Processes Matrix

Instructions:
Indicate the current relative contribution of each health care professional (or receptionist) to each of the following family practice medication processes by writing in the appropriate number from the scale. Consider all medication: prescription, over the counter and alternative treatment.

If you have not worked with certain professionals, please indicate your perception of their contribution.

The same number can be used more than once in each row.

There is a final question that asks you to indicate which professionals you have worked with before in a primary care setting.

1	**2**	**3**	**4**	**5**
No Contribution		**Some contribution**		**Major Contribution**

Medication Use Process	Family Physician	Family Practice Pharmacist	Nurse	Receptionist	Community Pharmacist
Make the diagnosis					
Determine if drug therapy needed					
Select best drug for patient; for example, consider contraindications, precautions, drug interactions, efficacy, best available evidence, cost, convenience					
Involve patient in decision making regarding medication choices					
Select best regimen, e.g. dosage form and dose based on individual characteristics (previous intolerance, renal and hepatic function etc.)					
Provide drug samples					
Identify prescribing errors					

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1	2	3	4	5
No Contribution		Some contribution		Major Contribution

Medication Use Process	Family Physician	Family Practice Pharmacist	Nurse	Receptionist	Community Pharmacist
Complete forms as required (e.g. coverage and insurance)					
Educate patient about the medication re: medication use, administration, monitoring, and addressing patient's concerns and questions during initial and ongoing therapy					
Update patient's medication profile and allergies in family medicine chart					
Monitor effectiveness and safety e.g. order lab tests at appropriate intervals or arrange for follow-up phone calls or appointments					
Monitor compliance					
Institute compliance/ adherence interventions as needed					
Receive and organize requests for prescription renewals					
Decide whether to continue medication, renew prescription, alter medication regimen or discontinue therapy					
Screen patients' medication lists to determine if potential drug-related problems					
Provide complete Medication Review, including patient interview, to identify drug-related problems					
Document medication-related information in the patient's family medicine chart					
Provide group patient education regarding medications					

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1	2	3	4	5
No Contribution		Some contribution		Major Contribution

Medication Use Process	Family Physician	Family Practice Pharmacist	Nurse	Receptionist	Community Pharmacist
Provide drug information to practitioners					
Teach medical students and residents about drug therapy					
Manage drug samples					

	Family Physician	Family Practice Pharmacist	Nurse	Receptionist	Community Pharmacist
I have worked with the following professionals in a primary health care setting	ڤ Yes ڤ No	ڤ Yes ڤ No	ڤ Yes ڤ No	ڤ Yes ڤ No	ڤ Yes ڤ No

If you had any difficulty completing certain sections, please state which ones and why:

_____

_____

_____

_____

_____

Participant Characteristics

1. Site: _____
2. Occupation (check one)
   family physician □ nurse □ office staff □ nurse practitioner □
   IMPACT pharmacist □ community pharmacist □ other : _____
3. How many years have you worked in family medicine practice? ____ N/A ____
4. Sex (check) male □ female □
5. Personal Academic Affiliation (check one)
   Intern □ Resident □ Fellow □
   Part-time/Adjunct faculty □ Full time faculty □ no faculty affiliation □

Please add any other comments to the back of this page

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Participant ID:

Measure # 21: Resources and Support for Self-Management (RSSM)

Contact Information:

- Contact information unavailable.

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Measure # 22a: Continuity of Care Practices Survey – Program Level (CCPS-P)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Jeanne A. Schaefer
Center for Health Care Evaluation
Veterans Affairs Palo Alto Health Care System
795 Willow Road (152)
Menlo Park, CA 94025, USA
Jeanne.Schaefer@va.gov

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- Any use of the measure instruments must be accompanied by the following citation: Schaefer, J. A**,** Cronkite, R. C., & Ingudomnukul, E. (2004). Assessing continuity of care practices in substance use disorder treatment programs. Journal of Studies on Alcohol, 65, 513-520. The measure owner requests that users send a copy of any modifications or alterations made to the instrument to Dr. Jeanne A. Schaefer (contact information listed above).

ID # | | | |

CONTINUITY OF CARE PRACTICES SURVEY (CCPS-P)

Your responses to this survey will help us gain a better understanding of the continuity of care practices currently used by clinicians in VA substance use disorder treatment programs.

Please respond to each question. If you do not want to answer a particular question, please circle the number beside it so that we know you did not skip it accidentally.

All questions on this survey concern the program listed below. Please check the information on the attached label and make any necessary corrections

Today's Date: _____

If you are <u>not</u> the person listed on the label, please provide the following information:

Your Name: _____

Job Title: _____

Telephone #: (_____) _____- _____ ext. _____

CCPS-P - Developed by Jeanne Schaefer, PhD
Center for Health Care Evaluation
VA Palo Alto Health Care System
795 Willow Road (152)
Menlo Park, CA 94025

GENERAL PROGRAM AND PATIENT INFORMATION

First, we want to get some general information about patients in your program (including all components). A "**rough ballpark"** estimate of the number or percent of patients is fine.

1. How many unique patients were treated in your program in FY (specify)?
   (Patients admitted more than once should be counted only once.)

   # of patients

2. What was the total full-time equivalent staff (FTEE) in your program in FY (specify)?
   (Include FTEE for positions that are vacant if currently recruiting for them.)

   # of FTEE

3. Approximately what percent of patients in your program in FY (specify) had the following characteristics at intake:

	Percent of patients (0 - 100%)
A. Were female?	
B. Were members of racial or ethnic minorities (African American, Hispanic, Asian or Pacific Islander, Native American)?	
C. Were dependent on both alcohol and other drugs?	
D. Had both a substance use disorder and a major psychiatric disorder (excluding PTSD)?	
E. Had a diagnosis of PTSD?	

DEFINITIONS – Please read these definitions before continuing with the survey.

The questions that follow ask about the substance use disorder services that your program provided during the **past 3 months**. Please keep these definitions in mind as you answer the questions.

Intensive inpatient/residential programs- For these programs, the **intensive** treatment component of the program means inpatient, residential, or domiciliary services that include more than detoxification and involve a stay of at least 14 days.

Outpatient programs (e.g., day hospital, intensive outpatient clinic) – For these programs, the **intensive** treatment component means that part of the program in which patients receive 3 or more hours of treatment per day for 3 or more days per week.

Continuing outpatient substance use disorder care – This is outpatient care (aftercare) that follows intensive inpatient or outpatient care and provides treatment less than 3 hours per day and less than 3 days per week.

4. In the past 3 months, was continuing outpatient substance use disorder care available **on-site** to patients at your VA facility after they completed intensive substance use disorder treatment? **NO** ☐ **YES** ☐

MAINTAINING CONTACT WITH PATIENTS

5. In the past 3 months, how often did continuing outpatient substance use disorder care staff in your program:

	Never/ rarely 1	Some-times 2	Fairly often 3	Almost always 4
A. Make reasonable attempts to contact patients within 3 working days of a missed outpatient continuing care substance use disorder appointment?	☐	☐	☐	☐
B. Send appointment reminders to patients prior to their scheduled outpatient continuing care substance use disorder appointments?	☐	☐	☐	☐

6. In the past 3 months, how often did program staff:

	Never/ rarely 1	Some-times 2	Fairly often 3	Almost always 4
A. Make reasonable attempts to call patients within 14 days of discharge from intensive treatment to find out if patients had contacted the services to which they had been referred?	☐	☐	☐	☐
B. Make reasonable attempts to get discharged patients back into treatment if they were not doing well?	☐	☐	☐	☐

Maintain Contact Subscale – Add scores for 5A-B and 6A-B and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 3 (the number of complete responses);l if no responses are missing, subtract 4.

FACILITATING TREATMENT ACROSS LEVELS OF CARE

Here, we ask about practices that aid patients' transition from intensive treatment to continuing outpatient care. Keep in mind that clinicians may rarely use some of these practices. Also, if the continuing outpatient care counselors mentioned in the questions (e.g., 7B, 8-A-E) are the same staff who provided patients' intensive treatment, mark the "Almost always" response.

7. How often in the past 3 months did staff in your program do the following **prior to patients' discharge from intensive treatment**:

	Never/ rarely 1	Some-times 2	Fairly often 3	Almost always 4
A. Arrange for patients to meet or talk to the counselor who would be providing them with continuing outpatient	☐	☐	☐	☐

substance use disorder care?

7. (CONTINUED)

How often in the past 3 months did staff in your program do the following **prior to patients' discharge from intensive treatment**:	**Never/ rarely 1**	**Some-times 2**	**Fairly often 3**	**Almost always 4**
B. Arrange for patients to attend continuing care outpatient substance abuse therapy groups during intensive treatment?	☐	☐	☐	☐
C. Arrange for patients to meet or talk to an AA, NA, or CA sponsor in their community?	☐	☐	☐	☐
D. Arrange for patients to attend an AA, NA, or CA meeting in their community during intensive treatment?	☐	☐	☐	☐
E. Secure drug-free or sober living arrangements for patients?	☐	☐	☐	☐
F. Have family members participate in patients' discharge planning for those patients who had contact with their family members?	☐	☐	☐	☐

Connect to Resources Subscale Part 1 – Add 7A-F and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 5, the number of complete responses.

8.

How often in the past 3 months did staff in the **intensive** treatment component of your program:	**Never/ rarely 1**	**Some-times 2**	**Fairly often 3**	**Almost always 4**
A. Speak directly (in person, by phone) with VA outpatient substance use disorder counselors to review patients' discharge summary prior to their first appointment with their counselors?	☐	☐	☐	☐
B. Work with outpatient substance use disorder counselors to jointly develop discharge plans for patients?	☐	☐	☐	☐
C. Notify outpatient substance use disorder counselors when patients who were being referred to them were discharged from intensive treatment?	☐	☐	☐	☐
D. Meet with or contact outpatient substance use disorder counselors at least once a month to review patients' progress and treatment?	☐	☐	☐	☐
E. Contact outpatient substance use disorder counselors within 14 days of patients' discharge from intensive treatment to check if patients were keeping continuing care outpatient substance use disorder appointments?	☐	☐	☐	☐

Coordinate Care Subscale – Add 8A-E and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 4, the number of complete responses.

9. Substance use disorder patients have many coexisting problems, and it's obviously not feasible for staff to address all of the problems of every patient. For each problem listed, please select the **one** referral action that staff in your program typically took prior to patients' discharge from intensive treatment during the past 3 months.

DESCRIPTIONS OF REFERRAL ACTIONS

1. Patient self-referral - Left it up to patients to refer themselves to an appropriate program.

2. Program name or brochure - Gave patients the name of a program (e.g. a referral slip) or written information (e.g., a program brochure), but did not give them the name of a specific person to contact.

3. Name & Phone # of contact - Gave patients the telephone number and name of a specific person to contact at a program.

4. Set up appointment - Set up an appointment for patients with a specific staff person at a program.

PATIENT PROBLEM	**STAFF ACTION**			
	Patient Self-referral 1	**Program Name or brochure 2**	**Name & phone # of contact 3**	**Set up appointment 4**
A. Medical problems	☐	☐	☐	☐
B. Employment problems	☐	☐	☐	☐
C. Housing problems	☐	☐	☐	☐
D. Psychiatric problems (excluding PTSD)	☐	☐	☐	☐
E. PTSD	☐	☐	☐	☐
F. Family Problems	☐	☐	☐	☐

Connect to Resources Part II – Add 9A-F and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 5, the number of complete responses.) To obtain the final Connect to Resources Subscale score add scores for Part I (page 4) and Part II.

DEFINITIONS – Please read these definitions before continuing with Question 10.

Substance use disorder programs vary considerably and program staff define counselor and case manager in many different ways. The definitions we present here may not match your program precisely. Please answer using the definition that best fits your program.

Primary counselor (e.g. a physician, nurse, psychologist, social worker, addiction therapist) - Provides most of the patient's psychological or psychosocial treatment.

Case Manager - Coordinates patient services across different levels of care, but is not the primary psychosocial counselor for patients. For example, the case manager might make sure that patients' needs (e.g., for housing or employment) are addressed and that patients get connected to community resources.

Primary counselor/case manager - Is a staff member who is the primary counselor for patients and also serves as their case manager.

10. In the past 3 months, approximately what percent of patients in the **intensive component** of your program:	**Percent of Patients (0-100%)**
A. Had the same **primary counselor** during intensive treatment and continuing outpatient substance use disorder care?	
B. Had the same **case manager** during intensive treatment and continuing outpatient substance use disorder care?	
C. Had the same **primary counselor/case manager** during intensive treatment and continuing outpatient substance use disorder care?	

Provider Continuity Subscale score Part I – Add 10A-C and divide by the number of responses without missing data, e.g., if one item has missing data, divide by 2, the number of complete responses.

11. In the past 3 months, roughly what percent of patients in your program were assigned to the same counselor, case manager, or addictions treatment team if they relapsed and needed intensive substance use disorder treatment again? ☐

To obtain the final Provider Continuity Subscale score – Add the Part I Provider Continuity Subscale score to the percent from Q11, then divide by 100.

YOU HAVE COMPLETED THIS SURVEY.

THANK YOU VERY MUCH FOR HELPING US BETTER UNDERSTAND TREATMENT PRACTICES IN VA SUBSTANCE USE DISORDER PROGRAMS.

Additional Information For Scoring Subscales With Missing Data.

When scoring the subscales, give the subscale a score if the respondent answers more than half of the items. For subscales with missing data, the sums for the subscale should be weighted by a correction factor which is the ratio of the maximum score if all items are complete over the maximum score for the number of items without missing data. For example, the maximum score for the Coordinate Care subscale is 15 if all 5 items are complete. If a respondent completes 4 items, the maximum score is 12. Consequently, the score for the subscale with one item missing (sum of 4 items) should be weighed by the ratio of 15 over 12, so that the range of values will be the same as it would have been if the respondent had completed all 5 items.

Measure # 22b: Continuity of Care Practices Survey – Individual Level (CCPS-I)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Jeanne A. Schaefer
Center for Health Care Evaluation
Veterans Affairs Palo Alto Health Care System
795 Willow Road (152)
Menlo Park, CA 94025, USA
Jeanne.Schaefer@va.gov

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Patient's Name:	ID #		

CONTINUITY OF CARE PRACTICES SURVEY (CCPS-I)

The primary counselor/case manager for the patient named above should complete this survey on the day that the patient is discharged from the intensive treatment component of your substance use disorder program.

Your responses to this discharge survey will help us to gain a better understanding of the continuity of care practices that clinicians are using in VA substance use disorder treatment programs.

DEFINITIONS - Please read these definitions before continuing with the survey.

These definitions may not match your program precisely. Please answer using the definition that best fits your program.

Intensive inpatient/residential programs- Here, the **intensive** treatment component of your program means inpatient, residential, or domiciliary services that include more than detoxification and involve a stay of at least 14 days.

Outpatient programs (e.g., day hospital, intensive outpatient clinic) - When we refer to the **intensive** treatment component, we mean that part of the program in which patients receive 3 or more hours of treatment per day for 3 or more days per week.

Continuing outpatient substance use disorder care – Is outpatient care (aftercare) that follows intensive inpatient or outpatient care and provides treatment less than 3 hours per day and less than 3 days per week.

Primary counselor (e.g. a physician, nurse, psychologist, social worker, addiction therapist) - Provides most of the patient's psychological or psychosocial treatment. Some primary counselors may also serve as the patient's case manager.

Case Manager - Coordinates patient services across different levels of care, but is not the primary psychosocial counselor for patients. For example, the case manager might make sure that program patients' needs (e.g., for housing or employment) are addressed and that patients get connected to community resources.

Today's Date: _____

Your Name: _____

Job Title: _____

CCPS-I Developed by Jeanne Schaefer, PhD
Center for Health Care Evaluation
VA Palo Alto Health Care System
795 Willow Road (152)
Menlo Park, CA 94025

PARTICIPATION IN TREATMENT

1. Date patient **entered** the intensive treatment component of your program? _____ Month Day Year

2. Date patient **left/will leave** the intensive treatment component of your program? _____ Month Day Year

3. Between the dates that this patient entered and left the intensive treatment component of your program, how many days did he/she actually attend the program? (**EXCLUDE DAYS** that the patient was absent from the program.) _____ # of days

4. Did this patient complete treatment? NO ☐ 0 YES ☐ 1

5. Will this patient receive continuing outpatient substance use disorder care after he/she leaves the intensive treatment component of your program? NO ☐ 0 YES ☐ 1

IF YES:

A. Was this patient given a continuing care appointment at discharge from Intensive treatment? NO ☐ 0 YES ☐ 1

B. Will most of this patient's continuing outpatient substance use disorder care (aftercare) be provided in your program by the **same person** who served as the patient's primary counselor/case manager during intensive substance use disorder treatment? NO ☐ 0 YES ☐ 1

6. Do you expect that this patient will be assigned to the same counselor, case manager, or addictions treatment team in your program if he/she relapses and needs intensive substance use disorder treatment again? NO ☐ 0 YES ☐ 1

(Provider Continuity Subscale – Sum scores for Q5B and Q6.)

SERVICES STAFF PROVIDED PRIOR TO DISCHARGE

Substance use disorder patients require many services. It's obviously not possible for staff to address all of the needs of every patient. Please check whether each service listed was provided to this patient. (If you or the staff who provided the patient's intensive treatment are the patient's outpatient continuing care counselor mentioned in 7A and & 7G,H, and I mark them "YES").

7. **Prior to** this patient's **discharge** from the intensive treatment component of the program, **did you or staff in the program**: NO 0 YES 1

A. Arrange for this patient to meet or talk to the counselor who would be providing him/her with continuing outpatient substance use disorder care? ☐ ☐

B. Arrange for this patient to attend outpatient continuing care substance use disorder therapy groups during intensive treatment? ☐ ☐

7. (Continued)
Prior to this patient's **discharge** from the intensive treatment component of this program, **did you or staff in the program**:

	NO 0	YES 1
C. Arrange for this patient to meet or talk to an AA, NA, or CA sponsor in his/her community?	☐	☐
D. Arrange for this patient to attend an AA, NA, or CA meeting in his/her community during intensive treatment?	☐	☐
E. Secure drug-free or sober living arrangements for this patient?	☐	☐
F. Have family members participate in this patient's discharge planning, if the patient has contact with his/her family members?	☐	☐
G. Speak directly (in person, by phone) with VA outpatient substance use disorder counselors to review this patient's discharge summary prior to his/her first appointment with the counselors?	☐	☐
H. Work with outpatient substance use disorder counselors to jointly develop a discharge plan for this patient?	☐	☐
I. Notify outpatient substance use disorder counselors to whom this patient was being referred when he/she was discharged from intensive treatment?	☐	☐

8. **For EACH patient problem** listed below, please write in the number of the one referral action (1-4 below) that best reflects the action you or staff in your program took with regard to this patient **prior to his/her discharge** from intensive treatment. Mark **NA** in the box if the patient does not have the problem.

Patient Problems

A. Medical Problems	☐	**B. Employment Problems**	☐	**C. Housing Problems**	☐
D. Psychiatric Problems (excluding PTSD)	☐	**E. PTSD**	☐	**F. Family Problems**	☐

Referral Actions

1. Left it up to the **patient to refer him/herself** to an appropriate program.
2. **Gave** this patient the **name of a program** (e.g. a referral slip) **or written information** (e.g., a program brochure) but **did not give** him/her the **name of a specific person to contact**.
3. **Gave** this patient the **telephone number** and **name** of a specific person to **contact** at a program.
4. **Set up an appointment** for this patient with a specific staff person at a program.

(Connect to Resources Subscale – If the mean score for all applicable problems in Q8A-F is less than or equal to 2, final score is sum of 7A-F. Otherwise, final score is sum of 7A-F plus 1.)

FACILITATING TREATMENT ACROSS LEVELS OF CARE

9. How likely is it that you or staff in your program will:

	Not very Likely 1	Some-what likely 2	Quite likely 3	Extremely likely 4
A. Make reasonable attempts to contact this patient within 3 days of a missed outpatient continuing care substance use disorder appointment?	☐	☐	☐	☐
B. Send appointment reminders to this patient prior to his/her scheduled outpatient continuing care substance use disorder appointments?	☐	☐	☐	☐
C. Make reasonable attempts to call this patient within 14 days of discharge from intensive treatment to find out if he/she has contacted the services to which he/she has been referred?	☐	☐	☐	☐
D. Make reasonable attempts to get this patient back into treatment if he/she is not doing well after discharge?	☐	☐	☐	☐
E. Meet with or contact outpatient substance use disorder counselors at least once a month to review this patient's progress and treatment?	☐	☐	☐	☐
F. Contact outpatient counselors within 14 days of the patient's discharge from intensive treatment to check if this patient is keeping outpatient continuing care substance use disorder appointments?	☐	☐	☐	☐

(Maintain Contact Subscale – Sum scores for Q9A-D and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 3 (the number of complete responses);I if no responses are missing, subtract 4.

(Coordinate Care Subscale – For Q9E-F, convert answers of 3 or 4 to 1, and answers of 1 or 2 to 0. Add the newly converted values of 9E-F to the sum of scores for Q7G-I on page 3.)

YOU HAVE COMPLETED THIS SURVEY.

THANK YOU VERY MUCH FOR HELPING US BETTER UNDERSTAND TREATMENT PRACTICES IN VA SUBSTANCE USE DISORDER PROGRAMS.

Additional Information For Scoring Subscales With Missing Data.

When scoring the subscales, give the subscale a score if the respondent answers more than half of the items. For subscales with missing data, the sums for the subscale should be weighted by a correction factor which is the ratio of the maximum score if all items are complete over the maximum score for the number of items without missing data. For example, the maximum score for the Maintain Contact subscale is 12 if all 4 items are complete. If a respondent completes 3 items, the maximum score is 9. Consequently, the score for the subscale with one item missing (sum of 3 items) should be weighed by the ratio of 12 over 9, so that the range of values will be the same as it would have been if the respondent had completed all 4 items.

Measure # 23: Program of All-Inclusive Care for the Elderly (PACE)

Contact Information:

- Contact information unavailable.

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Measure # 24: Measure of Processes of Care (MPOC-28)

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Measure # 25: Care Evaluation Scale for End-of-Life (CES)

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Measure # 26: Oncology Patients' Perceptions of the Quality of Nursing Care Scale (OPPQNCS)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Laurel E. Radwin, PhD, RN
Senior Scientist in Health Services Research
44 High Street
Chelmsford, MA 01824
laurel.e.radwin@gmail.com

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Additional Notes:

- The author recommends using the short form of the OPPQNCS as the psychometrics have been more rigorously tested through exploratory and confirmatory factor analyses as well as through the Multi-trait Analysis Program-Revised (MAP-R). The short form of the OPPQNCS reduces respondent burden while remaining true to the measure goals. Translations of the OPPQNCS are only available for the short form.

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1. **The nurses took time to answer my questions**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
2. **The nurses made sure I had what I needed**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
3. **The nurses comforted me when I needed it**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
4. **The nurses were genuinely concerned about me**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
5. **The nurses respected my dignity**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
6. **The nurses knew what I had been through**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never
7. **The nurses discussed care options with me**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐
8. **The nurses encouraged me to actively participate in my care**
   - ☐ Always
   - ☐ Almost Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Almost Never
   - ☐ Never

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9. The nurses told me which nurse was taking over when they were not there

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

10. The nurses arranged for the same nurses to care for me regularly

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

11. The nurses told me which nurse was primarily responsible for coordinating my care

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

12. The nurses were skillful

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

13. The nurses knew what they were doing

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

14. The nurses knew how to help me

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

15. In general, how would you describe the quality of the nursing care you received?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

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1. The nurses were skillful.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

2. The nurses knew how to care for someone with my condition.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

3. The nurses knew how to help me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

4. The nurses knew what they were doing.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

5. The nurses gave me accurate explanations about my care.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

6. The nurses took time to answer my questions.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

7. The nurses knew made sure I had what I needed.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

8. The nurses comforted me when I needed it.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

9. The nurses were genuinely concerned about me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

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10. The nurses respected my dignity.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

11. The nurses gave me support I needed.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

12. The nurses showed me they cared about my family and friends.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

13. The nurses remembered things about me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

14. The nurses checked on me often enough.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

15. The nurses were gentle with me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

16. The nurses took time to ask what I needed.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

17. The nurses took my concerns seriously.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

18. The nurses were kind to me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

19. The nurses came when I needed them.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

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20. The nurses made me feel like I mattered.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

21. The nurses spent time with me when I needed them.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

22. The nurses reacted quickly when something important happened.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

23. The nurses did what they could to make me comfortable.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

24. The nurses tried to help when I was having a difficult time.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

25. The nurses paid attention to what I said.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

26. The nurses addressed my needs promptly.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

27. The nurses made it easy to establish the relationship I wanted with them.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

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28. The nurses knew how I was feeling.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

29. The nurses knew what I had been through.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

30. The nurses knew how I was coping.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

31. The nurses knew how to help me when things were bothering me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

32. The nurses knew how to help me in ways that I liked.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

33. The nurses personalized my care to my particular needs..

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

34. The nurses helped me get the information I wanted.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

35. The nurses discussed care options with me.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

36. The encouraged me to actively participate in my care.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

37. The nurses correctly anticipated problems I might have because of my condition.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes

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- ☐ Almost Never
- ☐ Never

38. The nurses told me which nurse was taking over when they were not there.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

39. The nurses arranged for the same nurses to care for me regularly.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

40. The nurses told me which nurse was primarily responsible for coordinating my care.

- ☐ Always
- ☐ Almost Always
- ☐ Often
- ☐ Sometimes
- ☐ Almost Never
- ☐ Never

41. In general, how would you describe the quality of the nursing care you received?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Measure # 27: Care Coordination Services in Pediatric Practices

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- Contact information unavailable.

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Measure # 28: Collaboration and Satisfaction About Care Decisions (CSACD)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Judith Gedney Baggs, PhD, RN, FAAN
Elizabeth N. Gray Distinguished Professor
Oregon Health & Science University, School of Nursing
SN-4S
3455 SW US Veterans Hospital Road
Portland, OR 97239
P: (503) 494-1043; F: (503) 494-1012
baggsj@ohsu.edu

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Collaboration and Satisfaction about Care Decisions (CSACD)

Provider Code: _____ Patient Code: _____ Date: _____ Time: _____

These questions are related to the decision to transfer your patient. Please circle the number that best represents *your* judgment about the decision.

1. Nurses and physicians *planned together* to make the decision about care for this patient.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

2. *Open communication* between physicians and nurses took place as the decision was made for this patient.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

3. *Decision-making responsibilities* for this patient were *shared* between nurses and physicians.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

4. Physicians and nurses *cooperated* in making the decision.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

5. In making the decision, both *nursing and medical concerns* about this patient's needs were considered.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

6. Decision-making for this patient was *coordinated* between physicians and nurses.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

7. How much *collaboration* between nurses and physicians occurred in making the decision for this patient?

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

8. How *satisfied* are you with the way the decision was made for this patient, that is with the *decision-making process*, not necessarily with the decision itself?

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

9. How *satisfied* were you with the *decision* made for this patient?

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Measure # 29: Follow Up Care Delivery

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Measure # 30: Family Satisfaction in the Intensive Care Unit (FS-ICU 24)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Daren Keith Heyland MD, FRCPC, MSc.
Professor of Medicine
Angada 4 Room 5-416
Kingston General Hospital
6 Stuart Street
Kingston, ON K7L 2V7
P: +1(613) 549-6666 x. 3339; F: +1 (613) 548-2428
dkh2@queensu.ca

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Study ID number: ____ :____
site pt. #

Family Satisfaction with Care in the Intensive Care Unit©
FS-ICU (24)

How are we doing?

Your opinions about your family member's recent admission to the Intensive Care Unit (ICU)

Your family member was a patient in this ICU. You have been recorded as being the "next-of-kin". The questions that follow ask **YOU** about your family member's **most recent ICU admission**. We understand that there were probably many doctors and nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in **your overall assessment** of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. Please be assured that all responses are confidential. The Doctors and Nurses who looked after your family member will not be able to identify your responses.

DEMOGRAPHICS:

Please complete the following to help us know a little about you and your relationship to the patient.

1. I am**:** Male Female

2. I am _____ years old

3. I am the patient's:

Wife Husband Partner
Mother Father Sister Brother
Daughter Son Other (Please specify):_____

4. Before this most recent event, have you been involved as a family member of a patient in an ICU (Intensive Care Unit)?

Yes No

5. Do you live with the patient? Yes No

If no, then on average how often do you see the patient?

More than weekly Weekly Monthly Yearly Less than once a year

6. Where do you live? In the city where the hospital is located Out of town

How are we doing?
Your Opinions about your Family Member's ICU stay

PART 1: SATISFACTION WITH CARE

Please check one box that best reflects your views. If the question does not apply to your family member's stay then check the not applicable box (N/A).

	HOW DID WE TREAT YOUR FAMILY MEMBER (THE PATIENT)						
1.	**Concern and Caring by ICU Staff:** The courtesy, respect and compassion **your family member (the patient)** was given	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
	Symptom Management: How well the ICU staff assessed and treated your family member's symptoms.						
2.	**Pain**	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
3.	**Breathlessness**	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
4.	**Agitation**	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
	HOW DID WE TREAT YOU?						
5.	**Consideration of your needs:** How well the ICU staff showed an interest in your needs	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
6.	**Emotional support:** How well the ICU staff provided emotional support	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
7.	**Co-ordination of care:** The teamwork of all the ICU staff who took care of your family member	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
8.	**Concern and Caring by ICU**	1	2	3	4	5	6

How are we doing?
Your Opinions about your Family Member's ICU stay

	Staff: The courtesy, respect and compassion **you** were given	Excellent	Very Good	Good	Fair	Poor	N/A
	NURSES						
9.	**Skill and Competence of ICU Nurses:** How well the nurses cared for your family member.	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
10.	**Frequency of Communication With ICU Nurses**: How often nurses communicated to you about your family member's condition	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
	PHYSICIANS (All Doctors, including Residents)						
11.	**Skill and Competence of ICU Doctors:** How well doctors cared for your family member.	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
	THE ICU						
12.	**Atmosphere of ICU was?**	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
	THE WAITING ROOM						
13.	**The Atmosphere in the ICU Waiting Room was?**	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
14.	**Some people want everything done for their health problems while others do not want a lot done. How satisfied were you with the LEVEL *or amount* of health care your family member received in the ICU?**	1 Very Dissatisfied	2 Slightly Dissatisfied	3 Mostly Satisfied	4 Very Satisfied	5 Completely Satisfied	

How are we doing?
Your Opinions about your Family Member's ICU stay

PART 2: FAMILY SATISFACTION WITH DECISION-MAKING AROUND CARE OF CRITICALLY ILL PATIENTS

INSTRUCTIONS FOR FAMILY OF CRITICALLY ILL PATIENTS

This part of the questionnaire is designed to measure how you feel about YOUR involvement in decisions related to your family member's health care. In the Intensive Care Unit (ICU), your family member may have received care from different people. We would like you to think about all the care your family member received when you are answering the questions.

PLEASE CHECK ONE BOX THAT BEST DESCRIBES YOUR FEELINGS

INFORMATION NEEDS

1.	**Frequency of Communication With ICU Doctors**: How often doctors communicated to you about your family member's condition	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
2.	**Ease of getting information:** Willingness of ICU staff to answer your questions	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
3.	**Understanding of Information:** How well ICU staff provided you with explanations that you understood	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
4.	**Honesty of Information:** The honesty of information provided to you about your family member's condition	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
5.	**Completeness of Information:** How well ICU staff informed you what was happening to your family member and why things were being done.	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A
6.	**Consistency of Information:** The consistency of information provided to you about your family member's condition (Did you get a similar story from the doctor, nurse, etc.)	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor	6 N/A

PROCESS OF MAKING DECISIONS:

During your family member's stay in the ICU, many important decisions were made regarding the health care she or he received. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

7. **Did you feel included in the decision making process?**
   1 I felt very excluded
   2 I felt somewhat excluded
   3 I felt neither included nor excluded from the decision making process
   4 I felt somewhat included
   5 I felt very included

8. **Did you feel supported during the decision making process?**
   1 I felt totally overwhelmed
   2 I felt slightly overwhelmed
   3 I felt neither overwhelmed nor supported
   4 I felt supported
   5 I felt very supported

9. **Did you feel you had control over the care of your family member?**
   1 I felt really out of control and that the health care system took over and dictated the care my family member received
   2 I felt somewhat out of control and that the health care system took over and dictated the care my family member received
   3 I felt neither in control or out of control
   4 I felt I had some control over the care my family member received
   5 I felt that I had good control over the care my family member received

10. **When making decisions, did you have adequate time to have your concerns addressed and questions answered?**
    1 I could have used more time
    2 I had adequate time

How are we doing?
Your Opinions about your Family Member's ICU stay

If your family member died during the ICU stay, please answer the following questions (11-13). If your family member did not die please skip to question 14.

11**.** Which of the following best describes your views:

1 I felt my family member's life was prolonged unnecessarily
2 I felt my family member's life was slightly prolonged unnecessarily
3 I felt my family member's life was neither prolonged nor shortened unnecessarily
4 I felt my family member's life was slightly shortened unnecessarily
5 I felt my family member's life was shortened unnecessarily

12. During the final hours of your family member's life, which of the following best describes your views:

1 I felt that he/she was very uncomfortable
2 I felt that he/she was slightly uncomfortable
3 I felt that he/she was mostly comfortable
4 I felt that he/she was very comfortable
5 I felt that he/she was totally comfortable

13. During the last few hours before your family member's death, which of the following best describes your views:

1 I felt very abandoned by the health care team
2 I felt abandoned by the health care team
3 I felt neither abandoned nor supported by the health care team
4 I felt supported by the health care team
5 I felt very supported by the health care team

14**. Do you have any suggestions on how to make care provided in the ICU better?**

_____
_____
_____
_____
_____
_____

15**. Do you have any comments on things we did well?**

_____
_____
_____
_____

16. **Please add any comments or suggestions that you feel may be helpful to the staff of this hospital.**

We would like to thank you very much for your participation and your opinions. Please either return your completed survey to the designated person in the ICU or put it in the stamped, self-addressed envelope and mail it to us as soon as possible.

Measure # 31: Korean Primary Care Assessment Tool (KPCAT)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Jae Ho Lee, MD, MPH, PhD
Korean Primary Care Research Group(KPCRG)
Dept of Family Medicine, The Catholic University of Korea
P: 82-42-220-9247, 82-10-6778-7808
jaeholee@catholic.ac.kr

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Measure # 32: Primary Care Multimorbidity Hassles for Veterans with Chronic Illnesses

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Dr. Michael L. Parchman, MD, MPH
Audie Murphy VA Hospital
VERDICT (11C6)
7400 Merton Minter Blvd.
San Antonio, TX 78229-4404
parchman@uthscsa.edu

Copyright Details:

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Measure # 33: Primary Care Satisfaction Survey for Women (PCSSW)

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 34: Personal Health Records (PHR)

Contact Information:

- Contact information unavailable.

Shane Reti
Division of Clinical Informatics, Suite 400
1330 Beacon St.
Brookline, MA 02446, USA
sreti@post.harvard.edu

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 35: Picker Patient Experience (PPE-15)

Contact Information:

- Contact information unavailable.

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Measure # 36: Physician Office Quality of Care Monitor (QCM)

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument not yet obtained. Check back at a later date for an updated version of Appendix IV, which may contain a copy of the instrument.

Measure # 37: Patient Perceptions of Care (PPOC)

Contact Information:

- Contact information unavailable.

Copyright Details:

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Measure # 38a: PREPARED Survey – Patient Version

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Professor Karen Grimmer-Somers
Director, International Centre for Allied Health Evidence (iCAHE)
City East Campus, University of South Australia
North Terrace, Adelaide, SA 5000 08 83022769
P: +61-8-83022769
karen.grimmer-somers@unisa.edu.au

Copyright Details:

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Additional Notes:

- The measure instruments are also available from the following website: http://www.unisa.edu.au/cahe/Resources/DCP/Information.asp

Centre for Allied Health Evidence

CAHE Post-Discharge Patient Questionnaire

Section 1: Questions about you, the patient

1. Name of Hospital Ward from which you were discharged:

   _____

2. Home post code: _____

3. Today's Date: ____/_____/ 20_____

4. Your gender: Male / Female

5. Your date of birth: ____/_____/ 19_____

6. What was the reason for your last admission to hospital? :

   _____

7. **What date and day of the week were you discharged from hospital? :**

   _____

8. What time of the day were you discharged from hospital (include am or pm)? : _____

   _____

CONTACTS
www.unisa.edu.au/cahe
karen.grimmer-somers
@unisa.edu.au
Telephone (08) 8302 2769
Facsimile (08) 8302 2766

University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

University of South Australia | CAHE Centre for Allied Health Evidence

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Instrument Authors
Dr Karen Grimmer
Centre for Allied Health Evidence
University of South Australia
Telephone: (08) 8302 2769
Email: Karen.Grimmer@unisa.edu.au

THE UNIVERSITY OF ADELAIDE AUSTRALIA

John Moss
Department of Public Health
University of Adelaide (operating through Adelaide Research & Innovation)
Telephone: (08) 8303 4620
Email: john.moss@adelaide.edu.au

We are interested in how much information you received in hospital to prepare you for coping at home

Section 2: While you were in hospital:

1	How much information did you receive about the medications that you were to take home? *Please tick only one box*	As much as I needed Some, but not enough None Not taking **any** medications	O O O O
2	How much information did you receive about the side effects of the medications that you were to take at home? *Please tick only one box*	As much as I needed Some, but not enough None Not taking **any** medications	O O O O
3	Were you given **written** instructions about your medications? *Please tick only one box*	Yes No Not taking **any** medications	O O O
4	If **YES** did someone spend time explaining the written instructions? *Please tick only one box*	Yes No	O O
5	How much information did you receive on how you would **manage your usual activities** when you went home? (e.g. shopping, showering, bathing etc) *Please tick only one box*	As much as I needed Some, but not enough None	O O O
6	How much information did you receive on **community services** you might use once you went home? (e.g. Domicilary Care, District Nurse, Meals on Wheels etc) *Please tick only one box*	As much as I needed Some, but not enough None No services needed	O O O O
7	How much information did you receive on **equipment** you might need once you went home? (e.g. rails, shower chair, walking aids etc) *Please tick only one box*	As much as I needed Some, but not enough None No equipment needed	O O O O

Section 3: Before you were discharged from hospital:

1 Did anyone arrange community services for you to use at home? (*e.g. Domiciliary Care, District Nurse, Meals on Wheels etc)*
Please tick only one box

- Yes O
- No O
- No-one needed to:- Services were already in place O
- No-one needed to: No services needed O

1a. If you answered **YES**, have the services commenced? ***or*** If you answered **SERVICES WERE ALREADY IN PLACE**, have the services recommenced?

- Yes O
- No O

1b. If **NO**, why? …….

…….

2. Did anyone arrange equipment for you?
Please tick only one box

- Yes O
- No O
- No-one needed to:- Equipment already in place O
- No-one needed to: No equipment needed O

2a. If **YES**, do you have this equipment now?

- Yes O
- No O

2b. If **NO**, why? …….

…….

3. Was there any other information you would have liked while you were in hospital, to prepare you for coping at home?
Please tick only one box

- Yes O
- No O

3a. Please tell us more about this

……

……

Section IV: After the patient was told he/she could leave hospital:

1 How confident did **you** feel about managing at home?
Please tick only one box

- Confident O
- Unsure O
- Not confident O

Please tell us more about this

……

……

2 Were there any delays on the day you left hospital?
Please tick

- Yes O
- No O

3. If **YES,** what were the delays?
Please tick as many as you wish

- Transport O
- Medications O
- Don't know O
- Other O

Please indicate _____

Section V: Now you have been out of hospital for a while:

1 Has anything been worrying you about managing at home?
Please tick

- Yes O
- No O

1a. Please tell us more about this

……

……

2 Has anything been done to deal with your worries?
Please tick

- Yes O
- No O

2a. Please tell us more about this

……

……

---

3 Are you a carer for someone else?

For whom? (Spouse, child, other relative, friend, other)

Please circle

Yes O

No O

---

4. Have any unexpected problems occurred since you have been home?

Please tick

Yes O

No O

4a. Please tell us more about this

……

……

---

5. If the you have already received community services, have these services met your needs?…

Please tick

Everyone = you, the patient and any one else involved

Yes O

No O

5a. Please tell us more about this

……

……

---

6. If equipment was provided for the patient, did it make things easier for **you**?

Please tick

Yes O

No O

6a. Please tell us more about this

……

……

Section VI: in the first week after you left hospital

1 How many times did you see

*(Please put the number of times on **each** line)*

Your local doctor	Your specialist doctor
Physiotherapist	Chemist
Occupational Therapist	Meals on Wheels
Domiciliary Care	Other health professionals
District Nurse	Any other people who have helped you
Hospital outpatient/ Emergency clinic	*Please write who they were on the line below*

……

2 Did you receive any of the following services?

*(Please put the number of times on **each** line)*

Home modifications	O
Assistance with shopping	O
House cleaning	O
Other (Please indicate):	O

……

2 Have **you** had to spend any extra money as a result of the patient's visit to hospital? *(such as taxi fares, petrol, etc)*
Please tick

2a. If so, what are these costs approximately?

Taxi fares	$	Petrol	$
Extra shopping	$	Gap payments for health services	$
Extra chemist costs	$	Private Health Services	$
Other		*Please write who they were on the line below*	

……

3. Have **you** had to use any extra electricity as a result of looking after the patient?
Please tick

Yes	O
No	O

Section VII: Looking back to the time the patient left hospital

1 Overall, how prepared did you feel for returning to home?
Please tick

Totally prepared	O
Moderately prepared	O
Unprepared	O

2. Were there any particular aspects of your preparation for discharge whilst in hospital, that you would like to further comment on?

……

……

……

……

……

……

3. Were there any particular aspects of the patient's care after leaving hospital that you would like to comment further on?

……

……

……

……

……

……

There is also space for you to write on the back of this page if you want to write more

Section VIII: This sheet will be removed and used as a consent form for us to contact your doctor

1 When you were in hospital, what were you told to tell your usual doctor (GP) when you saw him/her?

……

……

---

2 Who is your usual doctor (GP) and what is his/her address?

……

……

---

3 Do you usually see any other doctors (GP's) *Please tick*

Yes O
No O

If **YES**, *How many* ----------

---

4 Do you consent to us contacting your usual GP about his/her views about your recent discharge from hospital? *Please tick*

Yes O
No O

If **YES**, please print your name and sign

PRINT YOUR NAME …… DATE: ……

SIGNATURE ……

Thank you for taking the time to complete this questionnaire. Please put it in an envelope and deliver to:

Name: _____

Office/Delivery: _____

_____

(Office use: for completed forms please enter the name of the nominated person and their address/office above)

Measure # 38b: PREPARED Survey – Carer Version

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Professor Karen Grimmer-Somers
Director, International Centre for Allied Health Evidence (iCAHE)
City East Campus, University of South Australia
North Terrace, Adelaide, SA 5000 08 83022769
P: +61-8-83022769
karen.grimmer-somers@unisa.edu.au

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Additional Notes:

- The measure instruments are also available from the following website: http://www.unisa.edu.au/cahe/Resources/DCP/Information.asp

Centre for Allied Health Evidence

CAHE Post-Discharge Carer Questionnaire

Section 1: Questions about you

1. Home post code: _____
2. Today's Date: ____/_____/ 20___
3. Your gender: Male / Female
4. Your date of birth: ____/_____/ 19___
5. Your relationship to the patient? :

   _____

6. **You** have been identified as the principal relative or friend who is looking after the patient in some way. Are there any other relatives or friends who also assist?

   Please tick: **Yes** O **No** O

7. Do you live at the same address as the patient?

   Please tick: **Yes** O **No** O

CONTACTS
www.unisa.edu.au/cahe
karen.grimmer-somers
@unisa.edu.au
Telephone (08) 8302 2769
Facsimile (08) 8302 2766

University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

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Instrument Authors
Dr Karen Grimmer
Centre for Allied Health Evidence
University of South Australia
Telephone: (08) 8302 2769
Email: Karen.Grimmer@unisa.edu.au

John Moss
Department of Public Health
University of Adelaide (operating through Adelaide Research & Innovation)
Telephone: (08) 8303 4620
Email: john.moss@adelaide.edu.au

We are interested in how much information you received FROM THE hospital to prepare you for coping at home with the patient

Section 2: While the patient was in hospital:

1	How much information did **you** receive about what medications were to be taken home by the patient? *Please tick only one box*	As much as I needed Some, but not enough None Patent is not taking any medications	o o o
2	How much information did you receive about the side effects of the medications to be taken home by the patient? *Please tick only one box*	As much as I needed Some, but not enough None Patent is not taking any medications	o o o
3	How much information did you receive on how you would manage the patient with personal care? (i.e. how you would help the patient with showering, bathing, dressing etc) *Please tick only one box*	As much as I needed Some, but not enough None	o o o
4	How much information did you receive about community services the patient might use at home? (E.g. Domiciliary Care, District Nurse, Meals on Wheels etc) *Please tick only one box*	As much as I needed Some, but not enough None Patent does not need any	o o o o
5	How much information did you receive on any equipment the patient might use at home? (E.g. rails, shower chair, walking aids etc) *Please tick only one box*	As much as I needed Some, but not enough None Patient does not need any	o o o o

6 Comments: Would you like to add anything to your answers on this page

Section 3: Before the patient was discharged from hospital:

1 Did anyone arrange community services for the patient ? (*e.g. Domiciliary Care, District Nurse, Meals on Wheels etc)* *Please tick only one box*

- Yes o
- No o
- No-one needed to:- Services were already in place o
- No-one needed to: No services needed o

If you answered **YES**, have the services commenced? ***or*** If you answered **SERVICES WERE ALREADY IN PLACE**, have the services recommenced?

- Yes o
- No o

2. Did anyone arrange equipment for the patient?
Please tick only one box

- Yes o
- No o
- No-one needed to:- Equipment already in place o
- No-one needed to: No equipment needed o

If **YES**, does the patient have this equipment now?

- Yes o
- No o

3. Did anyone talk to **<u>you</u>** about how **<u>you</u>** would manage **<u>your</u>** usual duties while caring for the patient? (*e.g. shopping, showering, bathing, dressing, toileting, feeding, mobility, transportation*)
Please tick correct box

- Yes o
- No o

4. Did you receive advice about services available for carers themselves? (eg carer respite services)

- Yes o
- No o

Please tick one box only

Please tell us more about this

5 Comments: Would you like to add anything to your answers on this page

Section IV: After the patient was told he/she could leave hospital:

1 How confident did **you** feel about managing at home?
Please tick only one box

- Confident o
- Unsure o
- Not confident o

1a. Please tell us more about this

.....

.....

.....

.....

2 Were there any delays in the patient leaving hospital? *Please tick*

- Yes o
- No o

2a. If **YES,** what were the delays?
Please tick as many as you wish

- Transport o
- Medications o
- Don't know o
- Other o

Please indicate _____

3. Comments: Would you like to add anything to your answers on this section?

.....

.....

Section V: Now the patient has been out of hospital for a while:

1 Do **you** have any health problems which make it harder for **you** to look after the patient?
Please tick

- Yes o
- No o

1a. Please tell us more about this

.....

.....

2 Has anything been worrying **you** about managing the patient at home? *Please tick*

- Yes o
- No o

2a. Please tell us more about this

……

……

---

3 Has anything been done to deal with your worries?

Please tick

Yes o
No o

3a. Please tell us more about this

……

……

---

4. Have any unexpected problems occurred since the patient left hospital to make **you** feel less confident about managing?

Please tick

Yes o
No o

4a. Please tell us more about this

……

……

---

5. If the patient has already received community services, have these services met everyone's needs?

Please tick

Everyone = you, the patient and any one else involved

Yes o
No o

5a. Please tell us more about this

……

……

---

6. If equipment was provided for the patient, did it make things easier for **you**?

Please tick

Yes o
No o

6a. Please tell us more about this

……

……

Section VI: in the first week after the patient left hospital

1 Did **your** health suffer so that **you** had to see any of the following people **more often** than usual?

*(Please put the number of times on **each** line)*

Your local doctor	Your specialist doctor
Physiotherapist	Chemist
Occupational Therapist	Meals on Wheels
Domiciliary Care	Other health professionals
District Nurse	Any other people who have helped you
Hospital outpatient/ Emergency clinic	*Please write who they were on the line below*
	……

---

2 Have **you** had to spend any extra money as a result of the patient's visit to hospital? *(such as taxi fares, petrol, etc)*
Please tick

Yes o
No o

2a. If so, what are these costs approximately?

Taxi fares	$	Petrol	$
Extra shopping	$	Gap payments for health services	$
Extra chemist costs	$	Private Health Services	$
Other		*Please write who they were on the line below*	
		……	

---

3. Have **you** had to use any extra electricity as a result of looking after the patient?
Please tick

Yes o
No o

3a. If **YES**, what have you used it for?

……

……

Section VII: Looking back to the time the patient left hospital

1	Overall, how prepared did you feel for caring for the patient at home? *Please tick*	Totally prepared	o
		Could have been better prepared	o
		Unprepared	o

2. Were there any particular aspects of the patient's preparation for discharge whilst in hospital, that **you** would like to further comment on?

……

……

……

……

……

……

……

3. Were there any particular aspects of the patient's care after leaving hospital, that you would like to comment further on?

……

……

……

……

……

……

……

……

There is also space for you to write on the back of this page if you want to write more

Thank you for taking the time to complete this questionnaire.

Please put it in an envelope and deliver to:

Name: _____

Office/Delivery: _____

(Office use: for completed forms please enter the name of the nominated person and their address/office above)

Measure # 38c: PREPARED Survey – Residential Care Staff Version

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Professor Karen Grimmer-Somers
Director, International Centre for Allied Health Evidence (iCAHE)
City East Campus, University of South Australia
North Terrace, Adelaide, SA 5000 08 83022769
P: +61-8-83022769
karen.grimmer-somers@unisa.edu.au

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Additional Notes:

- The measure instruments are also available from the following website: http://www.unisa.edu.au/cahe/Resources/DCP/Information.asp

Centre for Allied Health Evidence

CAHE Residential Care Staff Comments on Discharge Planning

Office use only

Patient's ID No _____ Hospital _____

Name of Residential Care Facility:_____

1. When were you made aware that the patient was being admitted to your facility?

		Please tick
a.	While patient was in hospital	☐
b.	On day of discharge	☐
c.	When the patient was in transit	☐
d.	When the patient arrived at your facilty	☐

2. Was anyone in your facility involved in planning this patient's discharge?

	Please tick
Yes	☐
No	☐

3. Did you receive sufficient information from the hospital about the patient's discharge health status?

	Please tick
More than sufficient	☐
Sufficient	☐
Less than sufficient	☐
Not at all	☐

3a. *Please outline any concerns*

_____

_____

CONTACTS
www.unisa.edu.au/cahe
karen.grimmer-somers
@unisa.edu.au
Telephone (08) 8302 2769
Facsimile (08) 8302 2766

University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

University of South Australia | CAHE Centre for Allied Health Evidence

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Instrument Authors
Dr Karen Grimmer
Centre for Allied Health Evidence
University of South Australia
Telephone: (08) 8302 2769
Email: Karen.Grimmer@unisa.edu.au

John Moss
Department of Public Health
University of Adelaide (operating through Adelaide Research & Innovation)
Telephone: (08) 8303 4620
Email: john.moss@adelaide.edu.au

4. Did you receive sufficient information from the hospital about the patient's medicines and medication management?

	Please tick
More than sufficient	☐
Sufficient	☐
Less than sufficient	☐
Not at all	☐

4a. *Please outline any concerns*

_____

_____

5. Are your staff able to manage this patient without problems?

	Please tick
Yes	☐
No	☐

5a. *Please outline any concerns*

_____

_____

6. Were you made aware by the hospital of any occupational health and safety issues for your service in managing this patient?

	Please tick
Yes	☐
No	☐

7. In your opinion, how adequate were the discharge plans to assist your staff to manage this patient?

	Please tick
More than adequate	☐
Adequate	☐
Less than adequate	☐
No information	☐

8. In your opinion, how adequate were the discharge plans to assist this patient to move into a residential care facility?

	Please tick
More than adequate	☐
Adequate	☐
Less than adequate	☐
No information	☐

9. Do you wish to comment further on any of the questions?

_____

_____

10. What aspects of this patient's discharge process were well performed?

_____

_____

11. How could the patient's discharge process have been improved?

_____

_____

Thank you for taking the time to complete this questionnaire.

Please put it in an envelope and deliver to:

Name: _____

Office/Delivery: _____

_____

(Office use: for completed forms please enter the name of the nominated person and their address/office above)

Measure # 38d: PREPARED Survey – Community Service Provider Version

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Professor Karen Grimmer-Somers
Director, International Centre for Allied Health Evidence (iCAHE)
City East Campus, University of South Australia
North Terrace, Adelaide, SA 5000 08 83022769
P: +61-8-83022769
karen.grimmer-somers@unisa.edu.au

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- Any use of the measure instruments must be accompanied by the following citation: Grimmer K, Moss J. Int J Qual Health Care. 2001;13(2):109-16. The measure owner requests that users send a copy of any modifications or alterations made to the instrument to Professor Karen Grimmer-Somers (contact information listed above).

Additional Notes:

- The measure instruments are also available from the following website: http://www.unisa.edu.au/cahe/Resources/DCP/Information.asp

Centre for Allied Health Evidence

CAHE Community Service Provider Comments on Discharge Planning

Office use only

Patient's ID No _____ Hospital _____

Name of Community Service:_____

Your classification (community service provider answering survey):

_____

1. When were you made aware that the client was to be discharged from hospital?

	Please tick
Client was still in hospital	☐
On day of discharge	☐
Within 1-2 days after discharge	☐
Within a week after discharge	☐
Longer than a week after discharge	☐
Not at all	☐

2. Was this sufficient notice for your organisation to respond to this client's immediate post-discharge needs?

	Please tick
More than sufficient	☐
Sufficient	☐
Less than sufficient	☐
Not at all	☐

3. Did you have an opportunity to accept or reject this referral?

	Please tick
Yes	☐
No	☐

CONTACTS
www.unisa.edu.au/cahe
karen.grimmer-somers
@unisa.edu.au
Telephone (08) 8302 2769
Facsimile (08) 8302 2766

University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

University of South Australia | CAHE Centre for Allied Health Evidence

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Instrument Authors
Dr Karen Grimmer
Centre for Allied Health Evidence
University of South Australia
Telephone: (08) 8302 2769
Email: Karen.Grimmer@unisa.edu.au

John Moss
Department of Public Health
University of Adelaide (operating through Adelaide Research & Innovation)
Telephone: (08) 8303 4620
Email: john.moss@adelaide.edu.au

4a. Was anyone in your organisation involved in planning this client's discharge from hospital?

Please tick

Yes ☐
No ☐

4b. Does the client or carer know why they have been referred to you?

Please tick

Yes ☐
No ☐

5a. Who organised the referral to your service? Please tick as many as required?

Please tick

Client ☐
Hospital staff member ☐
Carer / family member ☐
GP ☐
ACAT team ☐
Other health or community service worker? (whom?) ☐

_____

5b. If your service has a standard referral form, was this used for this referral?

Please tick

Standard form used ☐
Standard form available, but not used ☐
No standard form ☐

6. How did you receive the referral for this client?

Please tick as ,many as required

Telephone call ☐
Fax ☐
Electronic mail system ☐
Letter ☐
CIARR (Client Information and Referral Record) ☐
Other ☐

_____

7a. How adequate was the referral information about this client's post-discharge needs?

Please tick

More than adequate ☐
Adequate ☐
Less than adequate ☐
No information ☐

7b. If the information accompanying the referral was not adequate, what further information would have been helpful?

_____

_____

7c. Were the referral practices culturally appropriate for this client?

Please tick

Yes ☐
No ☐

If 'No', please comment:

_____

_____

8a. Are (will) your staff (be) able to provide adequate support for this client or carer??

Please tick

Yes ☐
No ☐

8b. Are (will) your staff (be) able to provide culturally appropriate services for this client or carer?

Please tick

Yes ☐
No ☐

8c. Were you given the client's language information?

Please tick

Yes ☐
No ☐

9. Did you have to refer the client or carer to service(s) more appropriate to his/ her post-discharge needs?

Please tick

Yes ☐
No ☐

10. Were you made aware of any occupational health and safety issues for your service in providing support for this client or carer?

Please tick

Yes ☐
No ☐

11a. Has an advocate (other than a family carer) assisted the client to contact your services?

Please tick

Yes ☐
No ☐

11b. In your opinion, was advocacy an effective way of organising appropriate community services for this client?

	Please tick
Yes	☐
No	☐

Please provide details if relevant:

_____

_____

12a. Does the client (&/or carer) recall being provided with sufficient information about available community services?

	Please tick
More than sufficient	☐
Sufficient	☐
Less than sufficient	☐
Not at all	☐

12b. In your opinion, what further information should the client &/or carer have received?

_____

_____

13. Has the client &/or carer formally taken up your service?

	Please tick
Yes	☐
No	☐

If 'No', what reason was given:

_____

_____

14a. If the client &/or carer has taken up your service, has the service commenced?

	Please tick
Yes	☐
No	☐

14b. If YES, how long was the waiting time before the service commenced?
Please insert number of weeks _____

14c. If NO, how long will the waiting time be before services commence?
Please insert number of weeks _____

15. In your opinion, how adequate were the discharge plans to assist this client to safely and successfully return to community living?

	Please tick
More than adequate	☐
Adequate	☐
Less than adequate	☐
No information	☐

Please comment: _____

_____

16a. Overall, how prepared did you feel the client was for returning home from hospital?

	Please tick
Sufficiently prepared	☐
Could have been better prepared	☐
Unprepared	☐

16b If the client has a carer, how prepared did you feel the carer was for the client to return home?

	Please tick
Sufficiently prepared	☐
Could have been better prepared	☐
Unprepared	☐

16c Was the referral to your service because the carer was unprepared?

	Please tick
Yes	☐
No	☐

17. What aspects of this client's referral process were well performed?

_____

_____

_____

18. How could the client's referral process have been improved?

_____

_____

_____

Thank you for taking the time to complete this questionnaire. Please put it in an envelope and deliver to:

Name: _____

Office/Delivery: _____

(Office use: for completed forms please enter the name of the nominated person and their address/office above)

Measure # 38e: PREPARED Survey – Medical Practitioner Version

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Professor Karen Grimmer-Somers
Director, International Centre for Allied Health Evidence (iCAHE)
City East Campus, University of South Australia
North Terrace, Adelaide, SA 5000 08 83022769
P: +61-8-83022769
karen.grimmer-somers@unisa.edu.au

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Additional Notes:

- The measure instruments are also available from the following website: http://www.unisa.edu.au/cahe/Resources/DCP/Information.asp

Centre for Allied Health Evidence

CAHE Medical Practitioner Comments on Discharge Planning

Office use only

Patient's ID No _____ Hospital _____

Doctor's Name (*please print clearly*):_____

1. When were you made aware that the client had been admitted to hospital?

		Please tick
a.	Prior to hospitalization	☐
b.	While patient was in hospital	☐
c.	On day of discharge	☐
d.	After the patient was discharged	☐
e.	Not at all	☐

2. Who made you aware of the admission?

		Please tick
a.	Hospital ward staff	☐
b.	Discharge Planner	☐
c.	Hospital medical staff	☐
d.	Ambulance	☐
e.	Patient	☐
f.	Patient's family / friends	☐
g.	Other (Please specify) _____	

3. When were you made aware that the patient was to be discharged?

	Please tick
Whilst patient was still in hospital	☐
On day of discharge	☐
Within 1-2 days after discharge	☐
Within a week after discharge	☐
Longer than a week after discharge	☐
Not at all	☐

CONTACTS
www.unisa.edu.au/cahe
karen.grimmer-somers
@unisa.edu.au
Telephone (08) 8302 2769
Facsimile (08) 8302 2766

University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

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Instrument Authors
Dr Karen Grimmer
Centre for Allied Health Evidence
University of South Australia
Telephone: (08) 8302 2769
Email: Karen.Grimmer@unisa.edu.au

John Moss
Department of Public Health
University of Adelaide (operating through Adelaide Research & Innovation)
Telephone: (08) 8303 4620
Email: john.moss@adelaide.edu.au

4. When were you made aware that the patient was to be discharged?

Please tick

- Hospital ward staff ☐
- Discharge Planner ☐
- Hospital medical staff ☐
- Ambulance ☐
- Patient ☐
- Patient's family / friends ☐
- Other (Please specify) _____

5. Were you involved in planning the patient's discharge?

Please tick

- Yes ☐
- No ☐

6. How soon after discharge did you receive any information (in any form) relating to this patient's hospital admission and discharge plans?

Please tick

- Within 1-2 days ☐
- Within a week ☐
- Longer than a week ☐
- Not received ☐
- Other (Please specify) _____

7. Was this sufficient notice to do something about this patient's post-discharge needs?

Please tick

- Sufficient ☐
- Less than sufficient ☐

8. Have you received adequate information about the patient's discharge health status?

Please tick

- Yes ☐
- No ☐

9. How did you receive the referral for this client?

Please tick as ,many as required

- Telephone call ☐
- Fax ☐
- Electronic mail system ☐
- Letter ☐
- Other ☐

_____

10. How adequate was the referral information about this client's post-discharge needs?

Please tick

- More than adequate ☐
- Adequate ☐
- Less than adequate ☐
- No information ☐

10.a If 'No', please explain your concerns:

_____

_____

11. Did you receive sufficient reasons for changes in medication? (For example, why one type of medication is used in preference to another?)?

	Please tick
More than sufficient	☐
Sufficient	☐
Less than sufficient	☐
Not at all	☐

11.a Please explain your concerns:

_____

_____

12. Are you aware of any community support services that are involved in providing assistance to the patient since discharge?

	Please tick
Yes	☐
No	☐

13. Has the patient voiced concerns that they have not been coping since discharge?

	Please tick
Yes	☐
No	☐

14. Has the patient's carer (if present) voiced concerns that they have not been coping since the patient was discharged?

	Please tick
Yes	☐
No	☐
Not applicable	☐

15. In your opinion, how adequate were the discharge plans to assist this patient to assume safe, independent community living?

	Please tick
More than adequate	☐
Adequate	☐
Less than adequate	☐
No information	☐

15.a If there were inadequate, or no, discharge plans, do you know why?

_____

_____

16. Have you any suggestions how the patient's discharge could have been improved?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Thank you for taking the time to complete this questionnaire.

Please put it in an envelope and deliver to:

Name: _____

Office/Delivery: _____

(Office use: for completed forms please enter the name of the nominated person and their address/office above)

Measure # 38f: PREPARED Survey – Modified Medical Practitioner Version

Contact Information:

- Contact information unavailable.

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Measure # 39: Health Tracking Household Survey

Contact Information:

- Contact information unavailable.

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Measure # 40: Adapted Picker Institute Cancer Survey

Contact Information:

- Contact information unavailable.

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Measure # 41: Ambulatory Care Experiences Survey (ACES)

Contact Information:

- Contact information unavailable.

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Measure # 42: Patient Perception of Continuity Instrument (PC)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Jason Chao, MD
Department of Family Medicine
Case Western Reserve University
10900 Euclid Ave
Cleveland, OH 44106
jxc19@case.edu

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Measure # 43: Jefferson Survey of Attitudes Toward Physician-Nurse Collaboration

Contact Information:

- Contact information unavailable.

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Measure # 44: Clinical Microsystem Assessment Diagnostic Tool (CMAD)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Thomas Huber, MS
P: (415) 350-2288
Thomaspatrick@mac.com

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Additional Notes:

- The Clinical Microsystem Assessment Diagnostic Tool (CMAD) was adapted by Thomas Huber from the Clinical Microsystem Assessment Tool (CMAT) [Nelson EC, Batalden PB, Huber TP, et al. Jt Comm J Qual Improv 2002;28(9):472-93]. The measure items mapped from the CMAD are nearly identical to those mapped for the CMAT. For further information on the CMAT, see the preceding pages.
- The CMAD provides an additional leadership diagnostic as well as 10 open-ended questions for each of the success characteristics. Open-ended questions were not mapped.
- The CMAD has been modified for use by front-line clinicians (T. Huber, personal communication, November 18, 2010).

Dear Healthcare Colleague,

The Clinical Microsystem Assessment Diagnostic is designed to help front line clinicians and managers improve performance in their natural work teams or "microsystems".[1] A microsystem consists of the unit based team, the work processes, and performance outcomes for a defined population of patients.

The CMAD diagnostic has been developed and shaped by research and consulting with high performing healthcare teams across the healthcare continuum in North America. We have been researching high performance in healthcare since 1995 and have worked at the unit level to improve healthcare performance.

My colleagues and I have learned that ten success characteristics are associated with high performing microsystems including; leadership, organizational support, front line team member focus, education and training, teamwork, patient focus, community orientation, performance improvement, process and systems orientation, information and communication).

More information can be found in the Joint Commission Article Series on High Performing Microsystems.[2]

*"Microsystems" consist of front line care delivery team members, work systems, and performance outcomes for a defined population of patients***.**

The CMAD assesses current levels of performance at the microsystem level and helps guide the improvement of quality, safety, service, and culture with front line care teams across each of the ten success characteristics associated with high performance.

We wish you continued success in improving microsystem performance in your local microsystems and organizations.

Kind Regards,

Thomas Huber, MS ECS

---

[1] The microsystem concept was developed by a group of researchers at Dartmouth Medical School by Paul Batalden, Eugene Nelson, Thomas Huber, Julie Johnson, and Margie Godfrey. The clinical Microsystems framework emerged from the 2000 Dartmouth Medical School research "Mapping and Disseminating Microsystems in Health Care", funded by the Robert Wood Johnson Foundation. Additional information can be found at www.clinicalmicrosystem.org, and Thomaspatrick@mac.com.

[2] Nelson, Batalden, Huber, et al: *Microsystems In Healthcare: Part 1. Learning from High Performing Front-Line Clinical Microsystems. Jt Comm J Qual Improv* 28:472-493, 2002.

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1. **Leadership:** *The role of leaders is to balance setting and reaching collective goals, and to empower individual autonomy and accountability, through building knowledge, respectful action, reviewing and reflecting.*

1(Low) 2 3 4 5 (High)

Leaders often tell team members how to do their job and leave little room for innovation and autonomy. Overall, we don't always foster collaboration and empowered team members.	We sometimes struggle to find the right balance between reaching performance goals and supporting and empowering the team. We have regular huddles and team meetings where everyone is encouraged to speak up.	We maintain a consistent purpose in our work, establish clear goals and expectations, and foster a respectful positive culture. We take time to build knowledge, review and reflect, and exchange ideas for building on our leadership.

Leadership Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. We have a consistent purpose and clear, established goals for the team.
   1 2 3 4 5
b. We balance setting and achieving group goals with individual autonomy and accountability.
   1 2 3 4 5
c. We continually foster a positive work culture and mutual respect between our professional disciplines.
   1 2 3 4 5
d. We are recognized as leaders and leading improvement by the larger organization
   1 2 3 4 5
e. We continually build knowledge and reflect on how to improve our leadership.
   1 2 3 4 5

Leadership Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. Does your leadership team meet on a regular basis to discuss leadership goals for the microsystem?

g. How are changes in the microsystem, i.e., new goals, communicated to the rest of the team members? Do you get buy-in ahead of time, do you involve everyone?

h. How frequently does your leadership team meet with team members to hear their ideas? How frequently do your individual disciplines meet to share improvement ideas?

i. Do you engage team members in building a positive culture in the microsystem and respect between the individual professional disciplines?

j. How often does your team engage in conversations about microsystem leadership? What kinds of topics for leadership do you discuss?

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2. Organizational Support: *The larger organization looks for ways to support the work of the microsystem and coordinate the hand-offs between microsystems.*

1(Low) 2 3 4 5 (High)

The larger organization isn't supportive in a way that provides recognition, information, and resources to enhance our work.	The larger organization is inconsistent and unpredictable in providing the recognition, information, and resources needed to enhance our work.	The larger organization provides timely recognition, information, and resources that enhance our work and makes it easier for us to meet the needs of our patients.

Organizational Support Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. The larger organization constantly looks for ways to connect to and facilitate the work of the microsystem.
   1 2 3 4 5
b. The larger organization facilitates the coordination and hand-offs between our microsystem and other microsystems in the hospital.
   1 2 3 4 5
c. The larger organization recognizes the work we do and provides recognition by congratulating our microsystem on achieving our goals formally and informally.
   1 2 3 4 5
d. The larger organization provides us with the right information and feedback, and provides good communication about changes that impact us.
   1 2 3 4 5
e. The larger organization provides us with right level of resources and support to help us take better care of our patients.
   1 2 3 4 5

Organizational Support Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. In what ways does the larger organization currently support the work of your microsystem?

g. How are changes that impact the microsystem, i.e., new goals or changes, communicated by the larger organization?

h. How often do you interact with the larger organization, what is the format?

i. In what ways could the larger organization show more support for the work of the microsystem?

j. How do you interact with other leadership team members in various microsystems throughout the hospital, what is the format?

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3. Team members Focus: *There is selective hiring of the right kind of people. The orientation process is designed to fully integrate new team members into culture and work roles. Expectations of team members are high regarding performance, continuing education, professional growth, and networking.*

1(Low) 2 3 4 5 (High)

We don't have a good selection process and orientation for new team members. We don't have a formal integration process for new members. There is a lack of continued education and professional growth.	We sometimes select for a good cultural fit and orient new members to our team. The microsystem is working on improving the education and training of team members, workload, and professional growth.	We always select for both cultural and performance in new team members. All of us feel as valued members of the microsystem. We have great education and training, workload management, and professional growth.

Team members Focus Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. Our hiring process is highly selective and potential team members are interviewed by our team to make sure the cultural fit is right.
   1 2 3 4 5
b. Our orientation process is designed to fully integrate new team members into our microsystem culture and work roles.
   1 2 3 4 5
c. We meet regularly to evaluate our team member performance and set high standards with regard to continuing education and professional growth.
   1 2 3 4 5
d. All of us feel as valued members of the microsystem and our input is very important to the way we do the work.
   1 2 3 4 5
e. We carefully align professional competencies with the work of the microsystem.
   1 2 3 4 5

Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. What is your selection and hiring process? Describe the selection and hiring process.

g. How are new members oriented to the microsystem? Describe the orientation process.

h. How do you evaluate performance of team members? How often is performance reviewed and discussed? During the evaluation are continued education and professional growth discussed and action plans created for everyone?

i. How do you incorporate team member input and ideas into the functioning of the microsystem? Please give one example of this.

j. How do you align professional competency and work roles in your microsystem?

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4. Education and Training: *All clinical microsystem team members have the responsibility for ongoing education and training, and for aligning daily work roles with training competencies.*

1(Low) 2 3 4 5 (High)

Training is accomplished in disciplinary silos, e.g., nurses train nurses, physicians train residents, etc. The educational efforts are not aligned with the flow of patient care, so that education becomes an add-on.	We recognize that our training could be different to reflect the needs of our microsystem, but we haven't made many changes yet. Some continuing education is available to everyone. Education and daily work is starting to be aligned.	There is a team approach to training, whether we are training team members, nurses or students. Education and patient care are integrated into the flow of our work. Continuing education for all team members is recognized as vital to our success.

Education and Training Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. We are very satisfied with our current training and teaching in our microsystem.
   1 2 3 4 5
b. We have a team approach to knowledge building. Training is interdisciplinary and across our various disciplines.
   1 2 3 4 5
c. Our educational efforts are tied to the flow of patient care. Our training occurs in real-time and at the bedside.
   1 2 3 4 5
d. Training programs are integrated and aligned with the work of the microsystem.
   1 2 3 4 5
e. Resources are available to all team members for ongoing education and training.
   1 2 3 4 5

Education and Training Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. How is the current training and education in your microsystem accomplished?

g. Is training accomplished by disciplinary silos, or do you have a team approach to knowledge building? Please describe.

h. Are your educational efforts tied to the flow of patient care? Please describe.

i. How do you integrate new programs and education into the work of the microsystem?

j. Are resources available to all team members for ongoing education and training? Please describe.

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5. Interdependence of Care Team: *The interaction of team members is characterized by trust, collaboration, willingness to help each other, appreciation of complementary roles, respect and recognition that all contribute individually to a shared purpose.*

1(Low) 2 3 4 5 (High)

Team members work independently and are responsible only for their part of the work. There is a lack of collaboration and a lack of appreciation for the importance of teamwork.	The care approach is interdisciplinary, but we are not always able to work together as an effective team. Individual contributions are weighed more heavily than being a team player.	Care is provided by an interdisciplinary team characterized by trust, collaboration, appreciation of complementary roles, and we recognize that all team members contribute to the shared purpose.

Interdependence of Care Team Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. The care approach in our microsystem is characterized by collaboration and an appreciation for complementary roles.
   1 2 3 4 5
b. There is a great respect and recognition that all team members contribute to a shared purpose.
   1 2 3 4 5
c. Our microsystem functions as a multidisciplinary team. Teamwork characterizes our way of doing our work.
   1 2 3 4 5
d. Although individuals in our microsystem are held accountable for their contribution to our work, there is a strong willingness to help each other.
   1 2 3 4 5
e. We have very good trust and respect among our various professional disciplines.
   1 2 3 4 5

Interdependence of Care Team Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. Tell us about your teamwork in the microsystem. How do your disciplines work together to deliver care?

g. To what degree is there collaboration in the microsystem and an appreciation for complementary roles?

h. Does everyone in your microsystem share a common purpose and shared goals? Are team members aware of how they contribute to the goals of the microsystem?

i. Give us an example of how team members exhibit a willingness to help each other.

j. To what degree is there respect and trust between the professional disciplines in the microsystem?

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6. Patient Focus: *The primary concern is to meet all patient needs – caring, listening, educating, and responding to special requests, innovating to meet patient needs, and great service.*

1(Low) 2 3 4 5 (High)

Many of us, including our patients and families would agree that we do not always provide patient centered care. We are not always clear about what patients want and need.	We are actively working to provide patient centered care and we are making progress toward consistently learning about and meeting patient needs.	We are effective in learning about and meeting patient and family needs – caring, listening, and responding to special requests and great service is the norm.

Patient Focus Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. The primary concern of the microsystem is to meet all patient needs.
   1 2 3 4 5
b. The microsystem can respond to individual needs of our patients, we are constantly innovating to make sure we meet the needs of our patients.
   1 2 3 4 5
c. The service flow and patient care process is centered on our patients.
   1 2 3 4 5
d. Most of our resources are based on our patients. We have the right amount of resources to provide great care to our patients.
   1 2 3 4 5
e. We collect data around patient centered care and know how well we are doing in terms of quality and service of care for our patients.
   1 2 3 4 5

Patient Focus Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. How do you go about assessing your microsystem in terms of patient centered care delivery?

g. Is your microsystem able to handle the individual needs of patients? How flexible is your microsystem to special needs of patients?

h. How does your microsystem deliver patient focused care, what steps have you taken to design patient centered care?

i. How well do your available resources meet the demands of delivering patient care?

j. Do you currently collect data on patient focused care; can you give us an example?

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7. Community and Market Focus: *The microsystem is a resource for the community; the community is a resource for the microsystem; the microsystem establishes excellent and innovative relationships with the community (patient and family population) it serves.*

1(Low) 2 3 4 5 (High)

We focus on the patients who come to our microsystem. We haven't implemented any outreach programs in our community. Patients and their families often make their own connections to the community resources they need.	We have tried a few outreach programs and have had some success, but it is not the norm for us to go out into the community or actively connect patients to the community resources that are available to them.	We are doing everything we can to understand our community. We actively employ resources to help us work with the community. We add to the community and we draw on resources from the community to meet patient needs.

Community and Market Focus Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. We have developed several ways of connecting to our community, i.e., outreach programs.
   1 2 3 4 5
b. Our microsystem is a resource for our community, and the community is a resource for our microsystem.
   1 2 3 4 5
c. We constantly strive to find innovative ways of connecting with our community.
   1 2 3 4 5
d. We collect data on our community and have measures that tell us how well we are doing.
   1 2 3 4 5
e. Our microsystem serves our community with resources from our larger organization.
   1 2 3 4 5

Community and Market Focus Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. Describe a few of your outreach programs, how are you currently connecting with your community?

g. What kinds of services are you offering to the community?

h. How often do you currently connect with your community?

i. What kinds of data do you collect on your community?

j. How does your community support the work of the microsystem?

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8. Performance Results: *Performance focuses on patient outcomes, avoidable costs, streamlining delivery, using data feedback, promoting positive competition, and open discussions about performance.*

1(Low) 2 3 4 5 (High)

We don't routinely collect data or measurements on the process or outcomes of the care we provide.	We often collect data on the outcomes of the care we provide and on some process of care.	Outcomes (clinical, satisfaction, financial, technical, safety) are routinely measured, reviewed by the team, and acted on to improve patient care.

Performance Results Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. We routinely measure outcomes on patient care and avoidable costs to streamline delivery processes.
   1 2 3 4 5
b. We routinely use data to improve the work of our microsystem across a variety of cost and quality metrics.
   1 2 3 4 5
c. We use a dashboard of metrics to assess the work of the microsystem, including clinical, satisfaction, financial, technical, and safety measures.
   1 2 3 4 5
d. We utilize performance metrics in our conversations with team members about how the microsystem is doing.
   1 2 3 4 5
e. We utilize our performance metrics in our discussions with the larger organization to report back how the microsystem is performing.
   1 2 3 4 5

Performance Results Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. What kinds of performance data do you currently collect on the functioning of your microsystem, i.e., clinical, process, satisfaction, quality, financial metrics?

g. How do you utilize the data that you gather on the functioning of the microsystem?

h. Do you share performance metrics with your team members? If yes, how so.

i. Do you share performance metrics with your larger organization? If yes, how so.

j. What kind of additional measures would you like in terms of improving your microsystem performance assessment?

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9. Process Improvement: *An atmosphere for learning and redesign is supported by the continuous improvement of care, use of benchmarking, frequent tests of change, and team members that have been empowered to innovate.*

1(Low) 2 3 4 5 (High)

The resources required (in the form of training, resources, and time) are rarely available to support improvement work. Any improvement activities we do are in addition to our daily work.	Some resources are available to support improvement work, but we don't use them as often as we could. Change ideas are implemented without much discipline. We aren't focusing on sustaining change yet.	There are significant resources to support continual improvement work. Studying, measuring, and improving care are sustained and are essential parts of our daily work.

Process Improvement Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. Studying, measuring, and improving care are essential parts of our daily work.
   1 2 3 4 5
b. We have an atmosphere of learning and redesign supported by continuous improvement of care, use of benchmarking, and frequent tests of change.
   1 2 3 4 5
c. Our team members are empowered to innovate with tools to improve the care processes.
   1 2 3 4 5
d. We often use quality improvement tools and techniques to improve our microsystem performance, i.e., fishbone diagrams, PDSA cycles, and flowcharting.
   1 2 3 4 5
e. We regularly share process measures and outcomes data with our team members to improve care for our patients.
   1 2 3 4 5

Process Improvement Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. How do you currently use quality improvement techniques and tools to improve your microsystem performance?

g. Have you ever flowcharted key clinical (quality, safety) processes? If yes, tell us about how you utilized this approach to improve care.

h. Do you currently train your team members in quality improvement? How is the training done?

i. How do you actively redesign work (service, resource) processes in your microsystem? How do you use benchmarking and tests of change (PDSA)?

j. How do you empower team members to innovate and make ongoing changes in the microsystem?

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10. Information and Communication: *Information is the connector – team members with patients, team members with team members, and team members and the larger organization. Communication is the HOW the information is transferred. Information Technology facilitates effective communication and multiple formal and informal channels exist.*

There are three key assessment areas for information and communication with patient and family members, team members, and the larger organization: (1) integration of information and communication with patients, (2) integration of information and communication between team members and with the larger organization, and (3) integration of information with technology.

Communication between Patients and Team Members:

1(Low) 2 3 4 5 (High)

Patients and family members have access to some standard information that is available to everyone but often leaves a gap between patients and the care team.	Patients and family members feel connected to the care team but don't always feel informed about the care they are receiving.	Patients and family members have a variety of ways to get the information they need and it can be customized to meet their individual learning styles. There is a strong connection between patients and the care team with joint understanding of care goals.

Communication between Team Members, and between Team Members and the Organization:

1(Low) 2 3 4 5 (High)

Relationships between team members are co-existent. We get the work done, but we really work in silos and sometimes it feels dysfunctional.	We are cooperative in the way we accomplish our work. We share information and we reach out beyond our disciplines on occasion.	We work collaboratively within our team and with other teams. We share information in real-time in a professional manner and there is mutual trust and respect for all team members.

Communication and Information Technology:

1(Low) 2 3 4 5 (High)

The technology we need to accomplish our work is either not available to us, or it is available but not effective. The information technology systems impede us from working collaboratively.	We have access to technology that enhances the work and care delivery, but it is not easy to use and seems to be cumbersome and not always efficient.	Technology enables us to work collaboratively by facilitating a smooth linkage between information and our patients by providing timely, effective access to the right information at the right time.

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Information and Communication Technology Questions: Individually and as a team, review and rate each question below (1 = low, 5 = high)

a. We have the right information available at the right time to treat patients. Our information technology gives us the right information at the right time.
   1 2 3 4 5
b. We have the right information available at the right time for our team members. Communication happens in real-time and team members and is characterized by mutual trust and respect.
   1 2 3 4 5
c. The information environment has been set-up to support the functioning of the microsystem. Patient, family members and team members have the correct information available to them in a timely manner.
   1 2 3 4 5
d. The larger organization provides us with the right information technology and provides good communication with us about changes that come up.
   1 2 3 4 5
e. There are effective communication channels with multiple formal and informal communication channels that support our work.
   1 2 3 4 5

Information and Communication Open Ended Questions: Review the questions below and discuss them during a team leadership meeting.

f. In what ways does the information environment (communication and information technology) support the functioning of the microsystem? In what ways can we improve the information environment?

g. In what ways can the larger organization support a more effective information environment in your microsystem?

h. What are your primary means of communicating with the rest of your team members? What are your communication strategies to enhance collaboration between team members, and between patients and team members?

i. How is information technology impacting care delivery in your unit? What are your improvement strategies to integrate emerging technology into the care delivery process?

j. How do you incorporate feedback from team members and patients into improving the communication and information environment?

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Measure # 44: Clinical Microsystem Assessment Tool (CMAT)

Contact Information:

- Contact information unavailable.

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Additional Notes:

- For a closely related instrument, see the Clinical Microsystem Assessment Diagnostic Tool (CMAD), which was adapted from the CMAT. A copy of the CMAD can be found on the preceding pages.

Measure # 45: Components of Primary Care Index (CPCI)

Contact Information:

- Contact information unavailable.

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Measure # 46: Relational Coordination Survey (RCS)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Jody Hoffer Gittell
jodyhoffergittel@brandeis.edu
http://www.relationalcoordination.org

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Relational Coordination Survey for Patient Care[1]

1. **How *frequently* do you communicate with care providers in these groups about _____ patients?**

Physicians	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐
Medical assistants	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐
Nurses	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐
Case managers	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐
Physical therapists	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐
Front office	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Constantly ☐

2. **Do care providers in these groups communicate with you in a *timely* way about _____ patients?**

Surgeons	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Medical assistants	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Nurses	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Case managers	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Physical therapists	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Front office	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐

3. **Do care providers in these groups communicate with you *accurately* about _____ patients?**

Physicians	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Medical assistants	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Nurses	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Case managers	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Physical therapists	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐
Front office	Never ☐	Rarely ☐	Occasionally ☐	Often ☐	Always ☐

[1] Questions should be customized to reflect the care process or patient population of interest. The responses should be customized to reflect the key provider groups involved in that care process or with that patient population. Please visit www://relationalcoordination.org for additional guidance.

4. When problems arise regarding the care of _____ patients, do care providers in these groups blame others or work with you to *solve the problem*?

Physicians	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐
Medical assistants	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐
Nurses	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐
Case managers	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐
Physical therapists	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐
Front office	Always Blame ☐	Mostly Blame ☐	Neither Blame Nor Solve ☐	Mostly Solve ☐	Always Solve ☐

5. How much do care providers in these groups *know* about your role in caring for _____ patients?

Physicians	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐
Medical assistants	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐
Nurses	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐
Case managers	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐
Physical therapists	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐
Front office	Nothing ☐	Little ☐	Some ☐	A lot ☐	Everything ☐

6. How much do care providers in these groups *respect* the role you play in caring for _____ patients?

Physicians	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Medical assistants	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Nurses	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Case managers	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Physical therapists	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Front office	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐

7. To what extent do care providers in these groups *share your goals* for the care of _____ patients?

Physicians	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Medical assistants	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Nurses	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Case managers	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Physical therapists	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐
Front office	Not at all ☐	A little ☐	Somewhat ☐	A lot ☐	Completely ☐

Measure # 47: Fragmentation of Care Index (FCI)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Constance Liu
cliu@aya.yale.edu

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Measure # 48: After Death Bereaved Family Member Interview

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

Joan M. Teno, M.D., M.S.
Center for Gerontology & Health Care Research
Brown University School of Medicine
121 South Main Street, Box G-121-612
Providence, RI 02912
P: (401) 863-9627; F: (401) 863-1742
Joan_Teno@Brown.edu

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TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Hospice Version

August 2000

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CONTENTS AT A GLANCE

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INFORMED CONSENT	MODULE: LAST MONTH OF LIFE QUESTIONS
CHECKING THE FACTS	EXAMPLE SURVEY INCLUDING 4 DOMAINS

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FAQS (FREQUENTLY ASKED QUESTIONS)

What can a hospice gain from administering this survey? Assessing quality of care is essential for quality improvement, and a family member's perspective is important for judging quality of care. This survey allows hospice staff to collect that perspective with a state of the art measurement tool geared specifically toward hospice care.

Is this a valid and reliable instrument? Yes. We have tested the instrument with a population of bereaved family members whose loved ones died in a hospital, nursing home, or while under hospice care. For these settings, the instrument is both reliable (i.e., it produces the same results when repeated and the items within each domain are correlated) and valid (i.e., it measures what it intends to measure). More information will be available in an upcoming article.

How should I administer the survey? An interviewer should administer the survey either over the telephone or in-person. (See "Instructions for Interviewers" below.) The survey is *not* intended to be self-administered by the respondent (e.g., mail-back surveys).

Why are the questions numbered out of sequence? The hospice version is based on a longer instrument and has been tailored to reflect hospice services. As a result, some questions from the longer instrument have been deleted and other questions have been moved. To maintain consistency across versions, we have retained the numbering from the original instrument – which means that the numbering for the hospice version appears out of sequence.

What do the colored circles around some of the questions mean? The instrument provides information on seven different aspects (or domains) of quality of care. We have color-coded the domains so that the questions pertaining to a specific domain all share the same color. (See "Instructions for Scoring" below.)

Do all of the questions in the main survey have to be asked, or can the survey be shortened? You can choose to focus on one or more specific domains. If you choose to limit your domains of interest, you should ask only those questions pertaining to your domains of interest (plus the questions included in "Introduction and Screening" and "Checking the Facts"). It is important to the validity and reliability of your results, though, that you include *all* of the questions within each domain of interest.

If you choose to limit the domains of interest, we suggest that a useful survey would include the following four domains: 1) physical comfort and emotional support, 2) promote shared decision making, 3) focus on individual, and 4) attend to the emotional and spiritual needs of the family. In this case, the interviewer would ask only those questions pertaining to the domains color-coded in blue, green, purple, and yellow (plus the questions included in "Introduction and Screening" and "Checking the Facts").

Note: Even if you limit your domains of interest, all respondents should answer the questions included in the "Introduction and Screening" and "Checking the Facts" sections. In addition, if the

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domains of interest are limited, then the numbers of the “skip to” questions may change.

Can I re-arrange the order of the questions? No. To maintain the validity and reliability of the instrument, the questions need to be asked in the order that they appear in the instrument (even when you are deleting the questions pertaining to domains in which you are not interested).

When should I use the optional questions and the last month of life module? This is your choice, depending on what information you need or want. The optional questions and the last month of life module are not included in the problem scores or overall ratings.

How should I analyze the results? The instrument is intended to identify opportunities to improve, so the data for the questions in the 7 domains are summarized as “problem scores”. Each domain has its own problem score. In addition, an overall rating is derived from the ratings questions. For more information, please see Chapter 4 of the Resource Guide.

Should the survey be used for individual patients or groups of patients? The survey was designed to be used with groups of people, but it can be used to assess the quality of care received by an individual patient. If the survey is used with a bereaved family member of a single patient and some of the questions do not apply to that patient/family member, then corresponding problem scores to the “skipped” questions will not be able to be computed. “Skipped” questions for some respondents is not a problem when groups of people are interviewed.

Is there a benchmark to which my scores can be compared? A current study will produce norms for the U.S., which will be available in Spring, 2002. Problem scores should be compared to norms, rather than to each other.

Who can I contact if I have questions?
By email, Joan_Teno@Brown.edu ; by phone, Jeff Edmonds at (401) 863-9630.

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INSTRUCTIONS FOR THE INTERVIEWER

- When conducting this interview (starting with the section titled "Introduction and Screening"), read all lowercase text aloud to the respondent.

- Instructions for interviewers are provided throughout the questionnaire in capital letters. Words appearing in capital letters are meant to guide the interviewer and should not be read aloud.

- Read instructions written in lowercase letters aloud to the respondent to guide him/her in answering.

- It is important to read questions in their entirety, exactly as written.

- Many of the questions are followed by ellipsis (…), which indicate that the interviewer should read the answer choices aloud to the respondent. Read *all* of the answer choices before pausing for a response. For yes/no questions, the answer categories should *not* be read aloud. These questions will not be followed by ellipsis, and the answer categories will appear in uppercase letters.

- The interviewer will often be expected to fill in personal information into survey questions. For example, the patient's name often in inserted into questions. The interviewer will know to substitute specific information when a word written in capital letters is enclosed in parentheses.

  EXAMPLE: Was [PATIENT] able to make decisions in the last week of life?
  READ AS: Was *Mr. Smith* able to make decisions in the last week of life?

  At times, the name of the hospice at which the patient died or the date on which the patient died should be inserted. The interviewer should be prepared with this information before beginning the interview.

- When lower case words appear in parentheses, the interviewer should choose the appropriate word.

  EXAMPLE: Was [PATIENT] unconscious or in a coma all of the time during the last week of (his/her) life?
  READ AS: Was Mrs. Jones unconscious or in a coma all of the time during the last week of *her* life?

- Words that are underlined should be emphasized when read aloud. It is important to the meaning of the question that these words are read with emphasis.

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- At times, optional words or phrases are provided in parentheses after a question. These words or phrases should be read only if the respondent requests further clarification. In all other cases, questions should be read as written, and the interviewer should *not* provide a definition or clarification to the respondent.

- Circle the number corresponding to the answer chosen by the respondent. For fill-in or open text answers, write in the appropriate information as stated by the respondent.

- Based on the answers to certain questions, it is sometimes logical to skip subsequent questions. For example, a surrogate who reports no pain should not then be asked about pain severity. Instruction for skips is generally provided within parentheses after a specific answer choice. If this answer is selected, move on to the question number indicated after that answer choice.

  EXAMPLE: Do you think this is where [PATIENT] would have most wanted to die?
  [ ] YES (SKIP TO 5)
  [ ] NO
  ACTION: If the respondent chooses YES, then skip to question 5.

- Be familiar with the instrument before conducting interviews. At times, for example, it is necessary to refer back to previous answers to determine if a question or a group of questions should be skipped.

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INSTRUCTIONS FOR SCORING

The purpose of this tool is to aid hospice staff in assessing and improving quality of care in 7 different aspects (or domains) of care. For 6 of the domains, the questions are summarized as "problem scores," with a higher number signifying more opportunity to improve. For the self-efficacy domain, key questions are summarized on a 3-point scale rather than as a problem score. In addition to the domains, the instrument produces an overall rating scale for patient focused, family centered care.

Each of the domains (listed below) is coded with a different color and symbol. Throughout the survey, all of the questions contributing to a domain's overall score are marked with that area's color. A question color-coded for a particular domain but not included in the list of "key questions" is necessary for obtaining an answer to a "key question" but is not itself included in the score.

Problem Scores

Physical comfort and emotional support
Key questions for problem score- D12a, D15, D15a, D16b, D17b

Inform and promote shared decision making
Key questions for problem score- C1a, C1b, C1c, D19, D26a, D27a, D28a, E1

Encourage advance care planning
Key questions for problem score- D2, D3, D4

Focus on individual
Key questions for problem score- D21, D22, D23, D24, D25, E2

Attend to the emotional and spiritual needs of the family
Key questions for problem score- E5, E5a, E5b, E6, E7, E8

Provide coordination of care
Key questions for problem score- C1d, C2/C2a, D15a, D18

Scale scores

^{D}c Support the self-efficacy of the family
Key questions for scale- D26b, D27b, D28b, D29b

R Overall Rating Scale for patient focused, family centered care
Key questions for scale- F1, F2, F3, F4, F5

Computing Domain Problem Scores and Scale Scores- *Upon receipt of your registration form*, Dr. Teno will send you a Scoring Packet. This Packet includes two items: 1) a pre-formatted Microsoft Excel spreadsheet for data entry and analysis, and 2) a Scoring Guide with information about using Excel as well as necessary codes for data entry.

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COVERSHEET

_____ _____ _____

Date of Interview **Interviewer ID** **Surrogate ID**

_____/_____/_____ _____/_____/_____

Patient Date of Birth **Patient Date of Death**

_____/_____/_____ _____/_____/_____

Date of Admit to Hospice Service **Date of Discharge (if different than date of death)**

Was patient under care of hospice during all of the last 7 days of life? _____

Patient Diagnosis: _____

_____

Patient Karnofsky Score:_____

Patient Marital Status: Married Widowed Divorced Single, never married

Patient Sex: M F

Patient Religious Preference: _____

Surrogate Name (First Last): _____

Surrogate Sex M F

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INTRODUCTION & SCREENING

Hello, may I speak to [SURROGATE FIRST NAME]?

My name is [YOUR NAME] and I am working on a study of patients of [HOSPICE]. I am sorry to hear of the loss of [PATIENT]. We are working on a program to help seriously ill patients and families make the best possible medical decisions. We are doing this by speaking to individuals such as yourself who can provide important information about the dying experience of a loved one. I realize that this is a difficult time for you, [SURROGATE'S FIRST NAME], but I wonder if I might ask you some questions. Is this a good time for us to talk?

[ ] YES →	(CONTINUE WITH INTERVIEW – GO TO QUESTION 1)
[ ] NO →	We will call you another time. When is usually a good time for you to talk? _____ [CONFIRM THAT SURROGATE WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

1. Can you tell me how you were related to [PATIENT NAME]?

   SPOUSE
   PARTNER

   CHILD
   DAUGHTER-IN-LAW/SON-IN-LAW
   PARENT
   SIBLING
   OTHER RELATIVE

   FRIEND
   OTHER (SPECIFY: _____)

2. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?

   [ ] YES (GO TO INFORMED CONSENT STATEMENT)
   [ ] NO

3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you?

   _____ (ALTERNATIVE PERSON)

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3a. What is this person's relationship to [PATIENT NAME]?

SPOUSE
PARTNER

CHILD
DAUGHTER/SON-IN-LAW
PARENT
SIBLING
OTHER RELATIVE
FRIEND
OTHER (SPECIFY:_____)

3b. We may want to interview [ALTERNATIVE PERSON], do you happen to have (his/her) full name, address and telephone number nearby.

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP CODE: _____

PHONE NUMBER: _____

INTERVIEWER: CONFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS.

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

INFORMED CONSENT

INTERVIEWER OR ADMINISTRATOR: IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S IRB.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as

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honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Finally, I have to tell you that my supervisor may monitor parts of the interview for quality control purposes.

Do you have any questions about who is doing the study or anything else pertaining to the study?

May we proceed with the interview?

[ ] YES (CONTINUE THE INTERVIEW -- GO TO QUESTION A)
[ ] NO (THANK RESPONDENT AND TERMINATE INTERVIEW)

CHECKING THE FACTS

A. Where did [PATIENT'S] death take place? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

[ ] AT HOME →	Was that in the patient's own home [ ], or in your home [ ], or in someone else's home [ ] ?
[ ] IN A HOSPITAL →	Was that in the Intensive Care Unit, [ ] YES [ ] NO → Was that in a palliative care or inpatient hospice unit? [ ] YES [ ] NO
[ ] NURSING HOME OR OTHER LONG-TERM CARE FACILITY →	Was that an inpatient hospice unit? [ ] YES [ ] NO
[ ] HOSPICE →	Do you mean an inpatient hospice unit? [ ] YES [ ] NO Do you mean residential housing provided by hospice? [ ] YES [ ] NO
[ ] IN TRANSIT TO A MEDICAL FACILITY	
[ ] SOMEWHERE ELSE →	SPECIFY:
[ ] DON'T KNOW	

A1. And our information is that [PATIENT] died in [DATE OF DEATH]. Is this correct?

[ ] YES
[ ] NO → In what month and year did (he/she) die? _____/_____

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A5. We're interested in finding out where [PATIENT] spent the last 30 days of (his/her) life. Let's start with where (he/she) was 30 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (30 DAYS BEFORE): _____ NUMBER OF DAYS: _____

[AS NEEDED: Did (he/she) go anywhere after that? Where was that? How long was (he/she) there? CONTINUE THROUGH THE DAY OF DEATH]

PLACE: _____ NUMBER OF DAYS: _____

PLACE: _____ NUMBER OF DAYS: _____

LAST PLACE: _____ NUMBER OF DAYS: _____

INTERVIEWER CHECK RE: (IN THAT LAST WEEK/WHILE UNDER CARE OF HOSPICE)
DETERMINE FROM THE COVER SHEET WHETHER PATIENT WAS UNDER CARE OF HOSPICE DURING THE LAST 7 DAYS OF HIS/HER LIFE.

IF YES → CHOOSE "IN THAT LAST WEEK"
IF NO → CHOOSE "WHILE UNDER CARE OF HOSPICE"

NOTE: LAST WEEK = 7 DAYS

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience (during (his/her) last week/while under care of hospice).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did <u>you</u> talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO C2)

C1a. (In that last week/ While under care of hospice), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of hospice), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

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C1c. (In that last week/ While under care of hospice), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of hospice), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

C2. (In that last week/ While under care of hospice), was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO

C2a. (In that last week/While under care of hospice), was it always clear to you which doctor was in charge of (his/her) care?

[ ] YES
[ ] NO

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

[ ] YES
[ ] NO (SKIP TO D5)
[ ] DON'T KNOW (SKIP TO D5)

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about (his/her) wishes about medical treatment?

[ ] YES
[ ] NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

[ ] YES
[ ] NO

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D4. (In that last week/ While under care of hospice), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

[ ] YES
[ ] NO

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

INTERVIEWER CHECK: DOES D5= YES **OR** D6 =YES?

[ ] YES
[ ] NO (SKIP TO A8)

D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of hospice?

[ ] YES
[ ] NO

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of hospice.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

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INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF HOSPICE?

[ ] YES (SKIP TO D18)
[ ] NO

D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of hospice), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. (In that last week/ While under care of hospice), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of hospice), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D18. (In that last week/ While under care of hospice), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

[ ] YES
[ ] NO

D19. (In that last week/ While under care of hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

D21. (In that last week/ While under care of hospice), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of hospice), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of hospice), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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D24. (In that last week/ While under care of hospice), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D27. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

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D28. At any time while [PATIENT] was involved with hospice did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

INTERVIEWER CHECK: DID PATIENT DIE AT HOME, SURROGATE'S HOME, OR SOMEONE ELSE'S HOME?

[ ] YES
[ ] NO (SKIP TO E1)

D29b. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

These next questions are about <u>your</u> experience (during [PATIENT'S] last week/while under care of hospice).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E5. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did someone from hospice talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E5a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E5b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospice)?

[ ] YES
[ ] NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

RATINGS

Now we would like you to rate some aspects of the care [PATIENT] received (in that last week/ while [PATIENT] was under care of hospice). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] <u>communicate</u> with (him/her) and the family about the illness and the likely outcomes of care?

R

[0 1 2 3 4 5 6 7 8 9 10]

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how would you rate how well those taking care of [PATIENT] provided <u>medical care that respected (his/her) wishes</u>?

R

[0 1 2 3 4 5 6 7 8 9 10]

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F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

R

[0 1 2 3 4 5 6 7 8 9 10]

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

R

[0 1 2 3 4 5 6 7 8 9 10]

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT]'s family and friends?

R

[0 1 2 3 4 5 6 7 8 9 10]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of hospice)?

[0 1 2 3 4 5 6 7 8 9 10]

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OPTIONAL SETS OF QUESTIONS

SOCIAL BACKGROUND

Now I have a few background questions about [PATIENT].

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

[ ] MARRIED
[ ] WIDOWED
[ ] DIVORCED
[ ] SEPARATED
[ ] NEVER MARRIED
[ ] DON'T KNOW

H2. Was (he/she) living alone?

[ ] YES
[ ] NO
[ ] DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE
[ ] DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, or something else?

[ ] PROTESTANT →	What denomination is that? _____
[ ] CATHOLIC	
[ ] JEWISH →	Is that Orthodox, Conservative, Reformed or something else? [ ] ORTHODOX [ ] CONSERVATIVE [ ] REFORM [ ] OTHER

[ ] SOMETHING ELSE (SPECIFY) → _____
[ ] NONE/ATHEIST

[ ] DON'T KNOW

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H5. Was [PATIENT] Hispanic or Latino?

[ ] YES
[ ] NO

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

[ ] WHITE
[ ] BLACK
[ ] ASIAN
[ ] SOMETHING ELSE (SPECIFY: _____)
[ ] DON'T KNOW

H7. What is your best guess of [PATIENT'S] household income in 1999 from all sources before taxes were taken out? Was it

[ ] under $11,000
[ ] $11,000-25,000
[ ] $25,000-50,000
[ ] more than $50,000

[ ] DON'T KNOW
[ ] REFUSED TO ANSWER

RESPONDENT DEMOGRAPHIC CHARACTERISTICS

Now I have a few last questions about <u>you</u>.

J1. How old were you on your last birthday?

_____ YEARS OLD

J2. What is the highest level of schooling you have completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE

[ ] DON'T KNOW

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J3. How would you rate your health? Would you say excellent, very good, good, fair, or poor?

[ ] EXCELLENT
[ ] VERY GOOD
[ ] GOOD
[ ] FAIR
[ ] POOR

J4. Is there anything else you'd like to share about [PATIENT]'s medical care in the last few days of life?

_____

_____

_____

J5. Is there anything else that you would like to share about how the medical care could have been improved for (PATIENT)?

_____

_____

_____

_____

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

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MODULE: LAST MONTH OF LIFE QUESTIONS

Now I want to ask about the care [PATIENT] received during (his/her) last month of life.

INTERVIEWER CHECK: IS THE ANSWER TO A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B4)
[ ] NO

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

[ ] YES
[ ] NO (SKIP TO B2)
[ ] DON'T KNOW (SKIP TO B2)

B1a. Did (he/she) get any help in dealing with (his/her) pain?

[ ] YES
[ ] NO (SKIP TO B2)

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)
[ ] DON'T KNOW (SKIP TO B3)

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)
[ ] DON'T KNOW (SKIP TO B4)

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

[ ] YES
[ ] NO

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO (SKIP TO B10)

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?

[ ] YES
[ ] NO

INTERVIEWER CHECK: IS A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B11)
[ ] NO

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

[ ] YES
[ ] NO (SKIP TO B11)

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

[ ] YES
[ ] NO

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

[0 1 2 3 4 5 6 7 8 9 10]

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EXAMPLE SURVEY INCLUDING 4 DOMAINS

- **Physical comfort and emotional support**
- **Inform and promote shared decision making**
- **Focus on individual**
- **Attend to the emotional and spiritual needs of the family**

INTRODUCTION AND SCREENING
INFORMED CONSENT
CHECKING THE FACTS

→ These sections remain intact.

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience (during (his/her) last week/while under care of hospice).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did you talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO D1)

C1a. (In that last week/ While under care of hospice), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of hospice), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of hospice), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of hospice.

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A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF HOSPICE?

[ ] YES (SKIP TO D19)
[ ] NO

D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of hospice), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. (In that last week/ While under care of hospice), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of hospice), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

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D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing?

☺

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

☺

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness?

☺

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

☺

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D19. (In that last week/ While under care of hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

D21. (In that last week/ While under care of hospice), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of hospice), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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D23. (In that last week/ While under care of hospice), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of hospice), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D28. At any time while [PATIENT] was involved with hospice did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

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D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

These next questions are about <u>your</u> experience (during [PATIENT'S] last week/while under care of hospice).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E5. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did someone from hospice talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E5a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E5b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospice)?

[ ] YES
[ ] NO

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E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide <u>you</u> - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

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TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Hospital Version

August 2000

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FAQS (FREQUENTLY ASKED QUESTIONS)

What can a hospital gain from administering this survey? Assessing quality of care is essential for quality improvement, and a family member's perspective is important for judging quality of care. This survey allows hospital staff to collect that perspective with a state of the art measurement tool geared specifically toward hospital care.

Is this a valid and reliable instrument? Yes. We have tested the instrument with a population of bereaved family members whose loved ones died in a hospital, nursing home, or while under hospice care. For these settings, the instrument is both reliable (i.e., it produces the same results when repeated and the items within each domain are correlated) and valid (i.e., it measures what it intends to measure). More information will be available in an upcoming article.

How should I administer the survey? An interviewer should administer the survey either over the telephone or in person. (See "Instructions for Interviewers" below.) The survey is *not* intended to be self-administered by the respondent (e.g., mail-back surveys).

Why are the questions numbered out of sequence? The hospital version is based on a longer instrument and has been tailored to reflect hospital services. As a result, some questions from the longer instrument have been deleted and other questions have been moved. To maintain consistency across versions, we have retained the numbering from the original instrument – which means that the numbering for the hospital version appears out of sequence.

What do the colored circles around some of the questions mean? The instrument provides information on seven different aspects (or domains) of quality of care. We have color-coded the domains so that the questions pertaining to a specific domain all share the same color. (See "Instructions for Scoring" below.)

Do all of the questions in the main survey have to be asked, or can the survey be shortened? You can choose to focus on one or more specific domains. If you choose to limit your domains of interest, you should ask only those questions pertaining to your domains of interest (plus the questions included in "Introduction and Screening" and "Checking the Facts"). It is important to the validity and reliability of your results that you include *all* of the questions within each domain of interest.

If you choose to limit the domains of interest, we suggest that a useful survey would include the following four domains: 1) physical comfort and emotional support, 2) promote shared decision making, 3) focus on individual, and 4) attend to the emotional and spiritual needs of the family. In this case, the interviewer would ask only those questions pertaining to the domains color-coded in blue, green, purple, and yellow (plus the questions included in "Introduction and Screening" and "Checking the Facts"). [See "Example Survey Including 4 domains" below.]

Note: Even if you limit your domains of interest, all respondents should answer the questions included in the "Introduction and Screening" and "Checking the Facts" sections. In addition, if the

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domains of interest are limited, then the “skip to” question numbers may change.

Can I re-arrange the order of the questions? No. To maintain the validity and reliability of the instrument, the questions need to be asked in the order that they appear in the instrument (even when you are deleting the questions pertaining to domains in which you are not interested).

When should I use the optional questions and the last month of life module? This is your choice, depending on what information you need or want. The optional questions and the last month of life module are not included in the problem scores or overall ratings.

How should I analyze the results? The instrument is intended to identify opportunities to improve, so the data for the questions in the 7 domains are summarized as “problem scores”. Each domain has its own problem score. In addition, an overall rating is derived from the ratings questions. For more information, please see Chapter 4 of the Resource Guide.

Should the survey be used for individual patients or groups of patients? The survey was designed to be used with groups of people, but it can be used to assess the quality of care received by an individual patient. If the survey is used with a bereaved family member of a single patient and some of the questions do not apply to that patient/family member, then problem scores that correspond with those questions that are “skipped” will not be able to be computed. “Skipped” questions for some respondents is not an issue when groups of people are interviewed.

Is there a benchmark to which my scores can be compared? A current study will produce norms for the U.S., which will be available in Spring, 2002. Problem scores should be compared to norms, rather than to each other.

Who can I contact if I have questions?
By email, Joan_Teno@Brown.edu ; by phone, Jeff Edmonds at (401) 863-9630.

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INSTRUCTIONS FOR THE INTERVIEWER

- When conducting this interview (starting with the section titled "Introduction and Screening"), read all lowercase text aloud to the respondent.

- Instructions for interviewers are provided throughout the questionnaire in capital letters. Words appearing in CAPITAL LETTERS are meant to guide the interviewer and should not be read aloud.

- Read instructions written in lowercase letters aloud to the respondent to guide him/her in answering.

- It is important to read questions in their entirety and exactly as written.

- Many of the questions are followed by ellipsis (…), which indicate that the interviewer should read the answer choices aloud to the respondent. Read *all* of the answer choices before pausing for a response. For "yes/no" questions, the answer categories should *not* be read aloud. These questions will not be followed by ellipsis, and the answer categories will appear in uppercase letters.

- The interviewer will often be expected to insert personal information into survey questions. For example, the patient's name often is inserted into questions. The interviewer will know to substitute specific information when a word written in capital letters is enclosed in parentheses.

  EXAMPLE: Was [PATIENT] able to make decisions in the last week of life?
  READ AS: Was *Mr. Smith* able to make decisions in the last week of life?

  At times, the name of the hospital at which the patient died or the date on which the patient died should be inserted. The interviewer should be prepared with this information before beginning the interview.

- When lower case words appear in parentheses, the interviewer should choose the appropriate word.

  EXAMPLE: Was [PATIENT] unconscious or in a coma all of the time during the last week of (his/her) life?
  READ AS: Was Mrs. Jones unconscious or in a coma all of the time during the last week of *her* life?

- Words that are underlined should be emphasized when read aloud. It is important to the meaning of the question that these words are read with emphasis.

- At times, optional words or phrases are provided in parentheses after a question. These

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words or phrases should be read only if the respondent requests further clarification. In all other cases, questions should be read as written, and the interviewer should *not* provide a definition or clarification to the respondent.

- Circle the number corresponding to the answer chosen by the respondent. For fill-in or open text answers, write in the appropriate information as stated by the respondent.

- Based on the answers to certain questions, it is sometimes logical to skip subsequent questions. For example, a surrogate who reports no pain should not then be asked about pain severity. Instruction for skips is generally provided within parentheses after a specific answer choice. If this answer is selected, move on to the question number indicated after that answer choice.

  EXAMPLE: Do you think this is where [PATIENT] would have most wanted to die?
  [ ] YES (SKIP TO 5)
  [ ] NO
  ACTION: If the respondent chooses YES, then skip to question 5.

- Be familiar with the instrument before conducting interviews. At times, for example, it is necessary to refer back to previous answers to determine if a question or a group of questions should be skipped.

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INSTRUCTIONS FOR SCORING

The purpose of this tool is to aid hospital staff in assessing and improving quality of care in 7 different aspects (or domains) of care. For 6 of the domains, the questions are summarized as "problem scores," with a higher number signifying more opportunity to improve. For the self-efficacy domain, key questions are summarized on a 3-point scale rather than as a problem score. In addition to the domains, the instrument produces an overall rating scale for patient focused, family centered care.

Each of the domains (listed below) is coded with a different color and symbol. Throughout the survey, all of the questions contributing to a domain's overall score are marked with that area's color. A question color-coded for a particular domain but not included in the list of "key questions" is necessary for obtaining an answer to a "key question" but is not itself included in the score.

Problem scores

Physical comfort and emotional support
Key questions for problem score- D12a, D15, D15a, D16b, D17b

Inform and promote shared decision-making
Key questions for problem score- C1a, C1b, C1c, D19, D26a, D27a, D28a, E1

Encourage advance care planning
Key questions for problem score- D2, D3, D4

Focus on individual
Key questions for problem score- D21, D22, D23, D24, D25, E2

Attend to the emotional and spiritual needs of the family
Key questions for problem score- E4, E4a, E4b, E6, E7, E8

Provide coordination of care
Key questions for problem score- C1d, C2, C2a, D15a, D18

Scale scores

D C Support the self-efficacy of the family
Key questions for problem score- D26b, D27b, D28b

R Overall Rating Scale for patient focused, family centered care
Key questions for scale- F1, F2, F3, F4, F5

Computing Domain Problem Scores and Scale Scores- *Upon receipt of your registration form*, Dr. Teno will send you a Scoring Packet. This Packet includes two items: 1) a pre-formatted Microsoft Excel spreadsheet for data entry and analysis, and 2) a Scoring Guide with information about using Excel as well as necessary codes for data entry.

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COVERSHEET

_____ _____ _____

Date of Interview **Interviewer ID** **Surrogate ID**

_____/_____/_____ _____/_____/_____

Patient Date of Birth **Patient Date of Death**

_____/_____/_____ _____/_____/_____

Date of Admit to Hospital **Date of Discharge**

Was patient under care of the hospital during all of the last 7 days of life? _____

Patient Diagnosis: _____

_____

Patient Karnofsky Score:_____

Patient Marital Status: Married Widowed Divorced Single, never married

Patient Sex: M F

Patient Religious Preference: _____

Surrogate Name (First Last): _____

Surrogate Sex M F

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INTRODUCTION & SCREENING

Hello, may I speak to [SURROGATE FIRST NAME]?

My name is [YOUR NAME] and I am working on a study of patients of [HOSPITAL]. I am sorry to hear of your loss of [PATIENT]. We are working on a program to help seriously ill patients and families make the best possible medical decisions. We are doing this by speaking to individuals such as yourself who can provide important information about the dying experience of a loved one. I realize that this is a difficult time for you, [SURROGATE'S FIRST NAME], but I wonder if I might ask you some questions. Is this a good time for us to talk?

[ ] YES →	(CONTINUE WITH INTERVIEW – GO TO QUESTION 1)
[ ] NO →	We will call you another time. When is usually a good time for you to talk? _____ [CONFIRM THAT SURROGATE WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

1. Can you tell me how you were related to [PATIENT NAME]?

   SPOUSE
   PARTNER

   CHILD
   DAUGHTER-IN-LAW/SON-IN-LAW
   PARENT
   SIBLING
   OTHER RELATIVE

   FRIEND
   OTHER (SPECIFY: _____)

2. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?

   [ ] YES (GO TO INFORMED CONSENT STATEMENT)
   [ ] NO

3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you?

   _____ (ALTERNATIVE PERSON)

   3a. What is this person's relationship to [PATIENT NAME]?

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SPOUSE
PARTNER

CHILD
DAUGHTER/SON-IN-LAW
PARENT
SIBLING
OTHER RELATIVE

FRIEND
OTHER (SPECIFY:_____)

3b. We may want to interview [ALTERNATIVE PERSON], do you happen to have (his/her) full name, address and telephone number nearby.

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP CODE: _____

PHONE NUMBER: _____

INTERVIEWER: CONFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS.

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

INFORMED CONSENT

INTERVIEWER OR ADMINISTRATOR: IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S IRB.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not

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sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Finally, I have to tell you that my supervisor may monitor parts of the interview for quality control purposes.

Do you have any questions about who is doing the study or anything else pertaining to the study?

May we proceed with the interview?

[ ] YES (CONTINUE THE INTERVIEW -- GO TO QUESTION A)
[ ] NO (THANK RESPONDENT AND TERMINATE INTERVIEW)

CHECKING THE FACTS

A. Where did [PATIENT'S] death take place? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

[ ] AT HOME →	Was that in the patient's own home [ ], or in your home [ ], or in someone else's home [ ] ?
[ ] IN A HOSPITAL →	Was that in the Intensive Care Unit, [ ] YES [ ] NO → Was that in a palliative care or inpatient hospice unit? [ ] YES [ ] NO
[ ] NURSING HOME OR OTHER LONG-TERM CARE FACILITY →	Was that an inpatient hospice unit? [ ] YES [ ] NO
[ ] HOSPICE →	Do you mean an inpatient hospice unit? [ ] YES [ ] NO Do you mean residential housing provided by hospice? [ ] YES [ ] NO
[ ] IN TRANSIT TO A MEDICAL FACILITY	
[ ] SOMEWHERE ELSE →	SPECIFY:
[ ] DON'T KNOW	

A1. And our information is that [PATIENT] died on [DATE OF DEATH]. Is this correct?

[ ] YES

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[ ] NO ⟶ In what month and year did (he/she) die? _____/_____

A5. We're interested in finding out where [PATIENT] spent the last 30 days of (his/her) life. Let's start with where (he/she) was 30 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (30 DAYS BEFORE): _____ NUMBER OF DAYS: _____

[AS NEEDED: Did (he/she) go anywhere after that? Where was that? How long was (he/she) there? CONTINUE THROUGH THE DAY OF DEATH]

PLACE: _____ NUMBER OF DAYS: _____

PLACE: _____ NUMBER OF DAYS: _____

LAST PLACE: _____ NUMBER OF DAYS: _____

INTERVIEWER CHECK: "IN THAT LAST WEEK" OR "WHILE UNDER CARE OF THE HOSPITAL"

DETERMINE FROM THE COVER SHEET WHETHER PATIENT WAS UNDER CARE OF THE HOSPITAL DURING THE LAST 7 DAYS OF HIS/HER LIFE.

IF YES ⟶ CHOOSE "IN THAT LAST WEEK"
IF NO ⟶ CHOOSE "WHILE UNDER CARE OF THE HOSPITAL"

NOTE: LAST WEEK = LAST 7 DAYS

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience during (his/her) (last week/while under care of the hospital).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the hospital), did <u>you</u> talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO C2)

C1a. (In that last week/ While under care of the hospital), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

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C1b. (In that last week/ While under care of the hospital), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of the hospital), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of the hospital), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

C2. (In that last week/ While under care of the hospital), was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO

C2a. (In that last week/While under care of the hospital), was it always clear to you which doctor was in charge of (his/her) care?

[ ] YES
[ ] NO

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D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

[ ] YES
[ ] NO (SKIP TO D5)
[ ] DON'T KNOW (SKIP TO D5)

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about (his/her) wishes about medical treatment?

[ ] YES
[ ] NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

[ ] YES
[ ] NO

D4. (In that last week/ While under care of the hospital), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

[ ] YES
[ ] NO

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

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INTERVIEWER CHECK: DOES D5= YES **OR** D6 =YES?

[ ] YES
[ ] NO (SKIP TO A8)

D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of the hospital?

[ ] YES
[ ] NO

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the hospital.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF THE HOSPITAL?

[ ] YES (SKIP TO D18)
[ ] NO

D12. (In that last week/ While under care of the hospital), was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

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D15. (In that last week/ While under care of the hospital), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of the hospital), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

D16. (In that last week/ While under care of the hospital), did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of the hospital), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D18. (In that last week/ While under care of the hospital), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

[ ] YES
[ ] NO

D19. (In that last week/ While under care of the hospital), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

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[ ] YES
[ ] NO

D21. (In that last week/ While under care of the hospital), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of the hospital), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of the hospital), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the hospital), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of the hospital), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to expect while (he/she) was dying?

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[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D27. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D28. At any time while [PATIENT] was in the hospital did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

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D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

These next questions are about <u>your</u> experience (during [PATIENT'S] last week/while [PATIENT] was under care of the hospital).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospital)?

[ ] YES
[ ] NO

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E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

RATINGS

Now we would like you to rate some aspects of the care [PATIENT] received (in that last week/ while (he/she) was under care of the hospital). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

R

[0 1 2 3 4 5 6 7 8 9 10]

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how

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would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

[0 1 2 3 4 5 6 7 8 9 10]

F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

R

[0 1 2 3 4 5 6 7 8 9 10]

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

R

[0 1 2 3 4 5 6 7 8 9 10]

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT'S] family and friends?

R

[0 1 2 3 4 5 6 7 8 9 10]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of the hospital)?

[0 1 2 3 4 5 6 7 8 9 10]

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OPTIONAL SETS OF QUESTIONS

SOCIAL BACKGROUND

Now I have a few background questions about [PATIENT].

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

[ ] MARRIED
[ ] WIDOWED
[ ] DIVORCED
[ ] SEPARATED
[ ] NEVER MARRIED
[ ] DON'T KNOW

H2. Was (he/she) living alone?

[ ] YES
[ ] NO
[ ] DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE
[ ] DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, or something else?

[ ] PROTESTANT →	What denomination is that? _____
[ ] CATHOLIC	
[ ] JEWISH →	Is that Orthodox, Conservative, Reformed or something else? [ ] ORTHODOX [ ] CONSERVATIVE [ ] REFORM [ ] OTHER

[ ] SOMETHING ELSE (SPECIFY) → _____
[ ] NONE/ATHEIST

[ ] DON'T KNOW

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H5. Was [PATIENT] Hispanic or Latino?

[ ] YES
[ ] NO

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

[ ] WHITE
[ ] BLACK
[ ] ASIAN
[ ] SOMETHING ELSE (SPECIFY: _____)
[ ] DON'T KNOW

H7. What is your best guess of [PATIENT'S] household income in 1999 from all sources before taxes were taken out? Was it

[ ] under $11,000
[ ] $11,000-25,000
[ ] $25,000-50,000
[ ] more than $50,000

[ ] DON'T KNOW
[ ] REFUSED TO ANSWER

RESPONDENT DEMOGRAPHIC CHARACTERISTICS

Now I have a few last questions about <u>you</u>.

J1. How old were you on your last birthday?

_____ YEARS OLD

J2. What is the highest level of schooling you have completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE

[ ] DON'T KNOW

J3. How would you rate your health? Would you say excellent, very good, good, fair, or poor?

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[ ] EXCELLENT
[ ] VERY GOOD
[ ] GOOD
[ ] FAIR
[ ] POOR

J4. Is there anything else you'd like to share about [PATIENT]'s medical care in the last few days of life?

_____

_____

_____

J5. Is there anything else that you would like to share about how the medical care could have been improved for [PATIENT]?

_____

_____

_____

_____

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MODULE: LAST MONTH OF LIFE QUESTIONS

Now I want to ask about the care [PATIENT] received during (his/her) last month of life.

INTERVIEWER CHECK: IS THE ANSWER TO A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B4)
[ ] NO

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

[ ] YES
[ ] NO (SKIP TO B2)
[ ] DON'T KNOW (SKIP TO B2)

B1a. Did (he/she) get any help in dealing with (his/her) pain?

[ ] YES
[ ] NO (SKIP TO B2)

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)
[ ] DON'T KNOW (SKIP TO B3)

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)
[ ] DON'T KNOW (SKIP TO B4)

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

[ ] YES
[ ] NO

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

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[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO (SKIP TO B10)

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?

[ ] YES
[ ] NO

INTERVIEWER CHECK: IS A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B11)
[ ] NO

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

[ ] YES
[ ] NO (SKIP TO B11)

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

[ ] YES
[ ] NO

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

[0 1 2 3 4 5 6 7 8 9 10]

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Domains Included

- **Physical comfort and emotional support**
- **Promote shared decision making**
- **Focus on individual**
- **Tend to the emotional and spiritual needs of the family**

INTRODUCTION AND SCREENING
INFORMED CONSENT
CHECKING THE FACTS

→ These sections remain intact.

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience during (his/her) (last week/while under care of the hospital).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the hospital), did you talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO D1)

C1a. (In that last week/ While under care of the hospital), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of the hospital), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of the hospital), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the hospital.

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A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

☺ _____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME PATIENT WAS UNDER THE CARE OF THE HOSPITAL?

[ ] YES (SKIP TO D19)
[ ] NO

NOTE: ONE WEEK = 7 DAYS

D12. (In that last week/ While under care of the hospital), was [PATIENT] on medicines to treat (his/her) pain?

☺

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

☺

[ ] YES
[ ] NO

D15. (In that last week/ While under care of the hospital), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

☺

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of the hospital), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

☺

[ ] YES
[ ] NO

D16. (In that last week/ While under care of the hospital), did (he/she) have trouble breathing?

☺

[ ] YES
[ ] NO (SKIP TO D17)

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[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of the hospital), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D19. (In that last week/ While under care of the hospital), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

D21. (In that last week/ While under care of the hospital), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of the hospital), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of the hospital), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY

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[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the hospital), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of the hospital), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D28. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

These next questions are about <u>your</u> experience (during [PATIENT'S] last week/while [PATIENT] was

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under care of the hospital).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of the hospital)?

[ ] YES
[ ] NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

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TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Nursing Home Version

August 2000

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FAQs (Frequently Asked Questions)

What can a nursing home gain from administering this survey? Assessing quality of care is essential for quality improvement, and a family member's perspective is important for judging quality of care. This survey allows nursing home staff to collect that perspective with a state of the art measurement tool geared specifically toward nursing home care.

Is this a valid and reliable instrument? Yes. We have tested the instrument with a population of bereaved family members whose loved ones died in a hospital, nursing home, or while under hospice care. For these settings, the instrument is both reliable (i.e., it produces the same results when repeated and the items within each domain are correlated) and valid (i.e., it measures what it intends to measure). More information will be available in an upcoming article.

How should I administer the survey? An interviewer should administer the survey either over the telephone or in person. (See "Instructions for Interviewers" below.) The survey is *not* intended to be self-administered by the respondent (e.g., mail-back surveys).

Why are the questions numbered out of sequence? The nursing home version is based on a longer instrument and has been tailored to reflect nursing home services. As a result, some questions from the longer instrument have been deleted and other questions have been moved. To maintain consistency across versions, we have retained the numbering from the original instrument – which means that the numbering for the nursing home version appears out of sequence.

What do the colored circles around some of the questions mean? The instrument provides information on seven different aspects (or domains) of quality of care. We have color-coded the domains so that the questions pertaining to a specific domain all share the same color. (See "Instructions for Scoring" below.)

Do all of the questions in the main survey have to be asked, or can the survey be shortened? You can choose to focus on one or more specific domains. If you choose to limit your domains of interest, you should ask only those questions pertaining to your domains of interest (plus the questions included in "Introduction and Screening" and "Checking the Facts"). It is important to the validity and reliability of your results that you include *all* of the questions within each domain of interest.

If you choose to limit the domains of interest, we suggest that a useful survey would include the following four domains: 1) physical comfort and emotional support, 2) promote shared decision making, 3) focus on individual, and 4) attend to the emotional and spiritual needs of the family. In this case, the interviewer would ask only those questions pertaining to the domains color-coded in blue, green, purple, and yellow (plus the questions included in "Introduction and Screening" and "Checking the Facts"). [See "Example Survey Including 4 domains" below.]

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Note: Even if you limit your domains of interest, all respondents should answer the questions included in the "Introduction and Screening" and "Checking the Facts" sections. In addition, if the domains of interest are limited, then the "skip to" question numbers may change.

Can I re-arrange the order of the questions? No. To maintain the validity and reliability of the instrument, the questions need to be asked in the order that they appear in the instrument (even when you are deleting the questions pertaining to domains in which you are not interested).

When should I use the optional questions and the last month of life module? This is your choice, depending on what information you need or want. The optional questions and the last month of life module are not included in the problem scores or overall ratings.

How should I analyze the results? The instrument is intended to identify opportunities to improve, so the data for the questions in the 7 domains are summarized as "problem scores". Each domain has its own problem score. In addition, an overall rating is derived from the ratings questions. For more information, please see Chapter 4 of the Resource Guide.

Should the survey be used for individual patients or groups of patients? The survey was designed to be used with groups of people, but it can be used to assess the quality of care received by an individual patient. If the survey is used with a bereaved family member of a single patient and some of the questions do not apply to that patient/family member, then problem scores that correspond with those questions that are "skipped" will not be able to be computed. "Skipped" questions for some respondents is not an issue when groups of people are interviewed.

Is there a benchmark to which my scores can be compared? A current study will produce norms for the U.S., which will be available in Spring, 2002. Problem scores should be compared to norms, rather than to each other.

Who can I contact if I have questions?
By email, Joan_Teno@Brown.edu ; by phone, Jeff Edmonds at (401) 863-9630.

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INSTRUCTIONS FOR THE INTERVIEWER

- When conducting this interview (starting with the section titled "Introduction and Screening"), read all lowercase text aloud to the respondent.

- Instructions for interviewers are provided throughout the questionnaire in capital letters. Words appearing in CAPITAL LETTERS are meant to guide the interviewer and should not be read aloud.

- Read instructions written in lowercase letters aloud to the respondent to guide him/her in answering.

- It is important to read questions in their entirety and exactly as written.

- Many of the questions are followed by ellipsis (…), which indicate that the interviewer should read the answer choices aloud to the respondent. Read *all* of the answer choices before pausing for a response. For "yes/no" questions, the answer categories should *not* be read aloud. These questions will not be followed by ellipsis, and the answer categories will appear in uppercase letters.

- The interviewer will often be expected to insert personal information into survey questions. For example, the patient's name often is inserted into questions. The interviewer will know to substitute specific information when a word written in capital letters is enclosed in parentheses.

  EXAMPLE: Was [PATIENT] able to make decisions in the last week of life?
  READ AS: Was *Mr. Smith* able to make decisions in the last week of life?

  At times, the name of the nursing home at which the patient died or the date on which the patient died should be inserted. The interviewer should be prepared with this information before beginning the interview.

- When lower case words appear in parentheses, the interviewer should choose the appropriate word.

  EXAMPLE: Was [PATIENT] unconscious or in a coma all of the time during the last week of (his/her) life?
  READ AS: Was Mrs. Jones unconscious or in a coma all of the time during the last week of *her* life?

- Words that are underlined should be emphasized when read aloud. It is important to the meaning of the question that these words are read with emphasis.

- At times, optional words or phrases are provided in parentheses after a question. These

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words or phrases should be read only if the respondent requests further clarification. In all other cases, questions should be read as written, and the interviewer should *not* provide a definition or clarification to the respondent.

- Circle the number corresponding to the answer chosen by the respondent. For fill-in or open text answers, write in the appropriate information as stated by the respondent.

- Based on the answers to certain questions, it is sometimes logical to skip subsequent questions. For example, a surrogate who reports no pain should not then be asked about pain severity. Instruction for skips is generally provided within parentheses after a specific answer choice. If this answer is selected, move on to the question number indicated after that answer choice.

  EXAMPLE: Do you think this is where [PATIENT] would have most wanted to die?
  [ ] YES (SKIP TO 5)
  [ ] NO
  ACTION: If the respondent chooses YES, then skip to question 5.

- Be familiar with the instrument before conducting interviews. At times, for example, it is necessary to refer back to previous answers to determine if a question or a group of questions should be skipped.

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INSTRUCTIONS FOR SCORING

The purpose of this tool is to aid nursing home staff in assessing and improving quality of care in 7 different aspects (or domains) of care. For 6 of the domains, the questions are summarized as "problem scores," with a higher number signifying more opportunity to improve. For the self-efficacy domain, key questions are summarized on a 3-point scale rather than as a problem score. In addition to the domains, the instrument produces an overall rating scale for patient focused, family centered care.

Each of the domains (listed below) is coded with a different color and symbol. Throughout the survey, all of the questions contributing to a domain's overall score are marked with that area's color. A question color-coded for a particular domain but not included in the list of "key questions" is necessary for obtaining an answer to a "key question" but is not itself included in the score.

Problem scores

Physical comfort and emotional support
Key questions for problem score- D12a, D15, D15a, D16b, D17b

Inform and promote shared decision making
Key questions for problem score- C1a, C1b, C1c, D19, D26a, D27a, D28a, E1

Encourage advance care planning
Key questions for problem score- D2, D3, D4

Focus on individual
Key questions for problem score- D21, D22, D23, D24, D25, E2

Attend to the emotional and spiritual needs of the family
Key questions for problem score- E4, E4a, E4b, E6, E7, E8

Provide coordination of care
Key questions for problem score- C1d, C2, C2a, D15a, D18

Scale scores

D_C Support the self-efficacy of the family
Key questions for problem score- D26b, D27b, D28b

R Overall Rating Scale for patient focused, family centered care
Key questions for scale- F1, F2, F3, F4, F5

Computing Domain Problem Scores and Scale Scores- *Upon receipt of your registration form*, Dr. Teno will send you a Scoring Packet. This Packet includes two items: 1) a pre-formatted Microsoft Excel spreadsheet for data entry and analysis, and 2) a Scoring Guide with information about using Excel as well as necessary codes for data entry.

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COVERSHEET

_____ _____ _____

Date of Interview **Interviewer ID** **Surrogate ID**

_____/_____/_____ _____/_____/_____

Patient Date of Birth **Patient Date of Death**

_____/_____/_____ _____/_____/_____

Date of Admit to Nursing Home **Date of Discharge**

Was patient under care of the nursing home during all of the last 7 days of life? _____

Patient Diagnosis: _____

_____

Patient Karnofsky Score: _____

Patient Marital Status: Married Widowed Divorced Single, never married

Patient Sex: M F

Patient Religious Preference: _____

Surrogate Name (First Last): _____

Surrogate Sex M F

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INTRODUCTION & SCREENING

Hello, may I speak to [SURROGATE FIRST NAME]?

My name is [YOUR NAME] and I am working on a study of patients of [NURSING HOME]. I am sorry to hear of your loss of [PATIENT]. We are working on a program to help seriously ill patients and families make the best possible medical decisions. We are doing this by speaking to individuals such as yourself who can provide important information about the dying experience of a loved one. I realize that this is a difficult time for you, [SURROGATE'S FIRST NAME], but I wonder if I might ask you some questions. Is this a good time for us to talk?

[ ] YES →	(CONTINUE WITH INTERVIEW – GO TO QUESTION 1)
[ ] NO →	We will call you another time. When is usually a good time for you to talk? _____ [CONFIRM THAT SURROGATE WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

1. Can you tell me how you were related to [PATIENT NAME]?

   SPOUSE
   PARTNER

   CHILD
   DAUGHTER-IN-LAW/SON-IN-LAW
   PARENT
   SIBLING
   OTHER RELATIVE

   FRIEND
   OTHER (SPECIFY: _____)

2. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?

   [ ] YES (GO TO INFORMED CONSENT STATEMENT)
   [ ] NO

3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you?

   _____ (ALTERNATIVE PERSON)

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3a. What is this person's relationship to [PATIENT NAME]?

SPOUSE
PARTNER

CHILD
DAUGHTER/SON-IN-LAW
PARENT
SIBLING
OTHER RELATIVE

FRIEND
OTHER (SPECIFY:_____)

3b. We may want to interview [ALTERNATIVE PERSON], do you happen to have (his/her) full name, address and telephone number nearby.

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP CODE: _____

PHONE NUMBER: _____

INTERVIEWER: CONFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS.

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

INFORMED CONSENT

INTERVIEWER OR ADMINISTRATOR: IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S IRB.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent. Your answers will be combined with the answers of other people for statistical analysis.

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It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Finally, I have to tell you that my supervisor may monitor parts of the interview for quality control purposes.

Do you have any questions about who is doing the study or anything else pertaining to the study?

May we proceed with the interview?

[ ] YES (CONTINUE THE INTERVIEW -- GO TO QUESTION A)
[ ] NO (THANK RESPONDENT AND TERMINATE INTERVIEW)

CHECKING THE FACTS

A. Where did [PATIENT'S] death take place? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

[ ] AT HOME →	Was that in the patient's own home [ ], or in your home [ ], or in someone else's home [ ] ?
[ ] IN A HOSPITAL →	Was that in the Intensive Care Unit, [ ] YES [ ] NO → Was that in a palliative care or inpatient hospice unit? [ ] YES [ ] NO
[ ] NURSING HOME OR OTHER LONG-TERM CARE FACILITY →	Was that an inpatient hospice unit? [ ] YES [ ] NO
[ ] HOSPICE →	Do you mean an inpatient hospice unit? [ ] YES [ ] NO Do you mean residential housing provided by hospice? [ ] YES [ ] NO
[ ] IN TRANSIT TO A MEDICAL FACILITY	
[ ] SOMEWHERE ELSE →	SPECIFY:
[ ] DON'T KNOW	

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A1. And our information is that [PATIENT] died on [DATE OF DEATH]. Is this correct?

[ ] YES
[ ] NO → In what month and year did (he/she) die? _____/_____

A5. We're interested in finding out where [PATIENT] spent the last 30 days of (his/her) life. Let's start with where (he/she) was 30 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (30 DAYS BEFORE): _____ NUMBER OF DAYS: _____

[AS NEEDED: Did (he/she) go anywhere after that? Where was that? How long was (he/she) there? CONTINUE THROUGH THE DAY OF DEATH]

PLACE: _____ NUMBER OF DAYS: _____

PLACE: _____ NUMBER OF DAYS: _____

LAST PLACE: _____ NUMBER OF DAYS: _____

INTERVIEWER CHECK: "IN THAT LAST WEEK" OR "WHILE UNDER CARE OF THE NURSING HOME"

DETERMINE FROM THE COVER SHEET WHETHER PATIENT WAS UNDER CARE OF THE NURSING HOME DURING THE LAST 7 DAYS OF HIS/HER LIFE.

IF YES → CHOOSE "IN THAT LAST WEEK"
IF NO → CHOOSE "WHILE UNDER CARE OF THE NURSING HOME"

NOTE: LAST WEEK = LAST 7 DAYS

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience during (his/her) (last week/while under care of the nursing home).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the nursing home), did <u>you</u> talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO C2)

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C1a. (In that last week/ While under care of the nursing home), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of the nursing home), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of the nursing home), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of the nursing home), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

C2. (In that last week/ While under care of the nursing home), was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO

C2a. (In that last week/While under care of the nursing home), was it always clear to you which doctor was in charge of (his/her) care?

[ ] YES
[ ] NO

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

[ ] YES
[ ] NO (SKIP TO D5)
[ ] DON'T KNOW (SKIP TO D5)

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D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about (his/her) wishes about medical treatment?

[ ] YES
[ ] NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

[ ] YES
[ ] NO

D4. (In that last week/ While under care of the nursing home), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

[ ] YES
[ ] NO

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

INTERVIEWER CHECK: DOES D5= YES **OR** D6 =YES?

[ ] YES
[ ] NO (SKIP TO A8)

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D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of the nursing home?

[ ] YES
[ ] NO

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the nursing home.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF THE NURSING HOME?

[ ] YES (SKIP TO D18)
[ ] NO

D12. (In that last week/ While under care of the nursing home), was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of the nursing home), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. (In that last week/ While under care of the nursing home), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

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D15a. (In that last week/ While under care of the nursing home), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

D16. (In that last week/ While under care of the nursing home), did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of the nursing home), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D18. (In that last week/ While under care of the nursing home), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

[ ] YES
[ ] NO

D19. (In that last week/ While under care of the nursing home), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

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D21. (In that last week/ While under care of the nursing home), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of the nursing home), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of the nursing home), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the nursing home), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

[ ] YES
[ ] NO

D25. (In that last week/ While under care of the nursing home), was there enough help with medications and getting dressings changed?

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was in the nursing home did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

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D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D27. At any time while [PATIENT] was in the nursing home did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D28. At any time while [PATIENT] was in the nursing home did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

DC

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

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These next questions are about your experience (during [PATIENT'S] last week/while [PATIENT] was under care of the nursing home).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of nursing home)?

[ ] YES
[ ] NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

RATINGS

Now we would like you to rate some aspects of the care [PATIENT] received (in that last week/ while (he/she) was under care of the nursing home). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] <u>communicate</u> with (him/her) and the family about the illness and the likely outcomes of care?

R

[0 1 2 3 4 5 6 7 8 9 10]

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how would you rate how well those taking care of [PATIENT] provided <u>medical care that respected (his/her) wishes</u>?

R

[0 1 2 3 4 5 6 7 8 9 10]

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F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

R

[0 1 2 3 4 5 6 7 8 9 10]

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

R

[0 1 2 3 4 5 6 7 8 9 10]

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT'S] family and friends?

R

[0 1 2 3 4 5 6 7 8 9 10]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of the nursing home)?

[0 1 2 3 4 5 6 7 8 9 10]

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OPTIONAL SETS OF QUESTIONS

SOCIAL BACKGROUND

Now I have a few background questions about [PATIENT].

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

[ ] MARRIED
[ ] WIDOWED
[ ] DIVORCED
[ ] SEPARATED
[ ] NEVER MARRIED
[ ] DON'T KNOW

H2. Was (he/she) living alone?

[ ] YES
[ ] NO
[ ] DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE
[ ] DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, or something else?

[ ] PROTESTANT →	What denomination is that? _____
[ ] CATHOLIC	
[ ] JEWISH →	Is that Orthodox, Conservative, Reformed or something else? [ ] ORTHODOX [ ] CONSERVATIVE [ ] REFORM [ ] OTHER

[ ] SOMETHING ELSE (SPECIFY) → _____
[ ] NONE/ATHEIST
[ ] DON'T KNOW

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H5. Was [PATIENT] Hispanic or Latino?

[ ] YES
[ ] NO

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

[ ] WHITE
[ ] BLACK
[ ] ASIAN
[ ] SOMETHING ELSE (SPECIFY: _____)
[ ] DON'T KNOW

H7. What is your best guess of [PATIENT'S] household income in 1999 from all sources before taxes were taken out? Was it

[ ] under $11,000
[ ] $11,000-25,000
[ ] $25,000-50,000
[ ] more than $50,000

[ ] DON'T KNOW
[ ] REFUSED TO ANSWER

RESPONDENT DEMOGRAPHIC CHARACTERISTICS

Now I have a few last questions about <u>you</u>.

J1. How old were you on your last birthday?

_____ YEARS OLD

J2. What is the highest level of schooling you have completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR AA DEGREE
[ ] COLLEGE GRADUATE
[ ] ADVANCED DEGREE

[ ] DON'T KNOW

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J3. How would you rate your health? Would you say excellent, very good, good, fair, or poor?

[ ] EXCELLENT
[ ] VERY GOOD
[ ] GOOD
[ ] FAIR
[ ] POOR

J4. Is there anything else you'd like to share about [PATIENT]'s medical care in the last few days of life?

_____

_____

_____

J5. Is there anything else that you would like to share about how the medical care could have been improved for [PATIENT]?

_____

_____

_____

_____

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

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MODULE: LAST MONTH OF LIFE QUESTIONS

Now I want to ask about the care [PATIENT] received during (his/her) last month of life.

INTERVIEWER CHECK: IS THE ANSWER TO A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B4)
[ ] NO

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

[ ] YES
[ ] NO (SKIP TO B2)
[ ] DON'T KNOW (SKIP TO B2)

B1a. Did (he/she) get any help in dealing with (his/her) pain?

[ ] YES
[ ] NO (SKIP TO B2)

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)
[ ] DON'T KNOW (SKIP TO B3)

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

[ ] YES
[ ] NO (SKIP TO B3)

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

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B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)
[ ] DON'T KNOW (SKIP TO B4)

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO B4)

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

[ ] YES
[ ] NO

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO (SKIP TO B10)

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?

[ ] YES
[ ] NO

INTERVIEWER CHECK: IS A8 [IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO 30 DAYS (1 MONTH)?

[ ] YES (SKIP TO B11)
[ ] NO

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

[ ] YES
[ ] NO (SKIP TO B11)

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

[ ] YES
[ ] NO

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

[0 1 2 3 4 5 6 7 8 9 10]

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EXAMPLE SURVEY INCLUDING 4 DOMAINS OF INTEREST

Domains Included

- **Physical comfort and emotional support**
- **Promote shared decision making**
- **Focus on individual**
- **Tend to the emotional and spiritual needs of the family**

INTRODUCTION AND SCREENING
INFORMED CONSENT
CHECKING THE FACTS

→ These sections remain intact.

DOMAIN QUESTIONS

These next questions are about [PATIENT'S] experience during (his/her) (last week/while under care of the nursing home).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the nursing home), did you talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO D1)

C1a. (In that last week/ While under care of the nursing home), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of the nursing home), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of the nursing home), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

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Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the nursing home.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME PATIENT WAS UNDER THE CARE OF THE NURSING HOME?

[ ] YES (SKIP TO D19)
[ ] NO

NOTE: ONE WEEK = 7 DAYS

D12. (In that last week/ While under care of the nursing home), was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of the nursing home), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. (In that last week/ While under care of the nursing home), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of the nursing home), was there ever a time when

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one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

D16. (In that last week/ While under care of the nursing home), did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of the nursing home), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D19. (In that last week/ While under care of the nursing home), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

D21. (In that last week/ While under care of the nursing home), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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D22. (In that last week/ While under care of the nursing home), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of the nursing home), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the nursing home), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of the nursing home), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was under care of the nursing home did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

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D27. At any time while [PATIENT] was under care of the nursing home did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D28. At any time while [PATIENT] was under care of the nursing home did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

These next questions are about <u>your</u> experience (during [PATIENT'S] last week/while under care of the nursing home).

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often did you have concerns about [PATIENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

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E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of the nursing home)?

[ ] YES
[ ] NO

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide <u>you</u> - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

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E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********

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Measure # 49: Schizophrenia Quality Indicators for Integrated Care

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Measure # 50: Degree of Clinical Integration Measures

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Measure # 51: National Survey for Children's Health (NSCH)

Contact Information:

- For questions regarding this measure and for permission to use it, contact:

The Child and Adolescent Health Measurement Initiative (CAHMI)
P: (503) 494-1930
cahmi@ohsu.edu

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National Survey of Children's Health (NSCH), 2007

Guide to Topics & Questions Asked

Initial Screening and Sampling

The interviewer begins by asking how many children live in the household and the age of each person under 18 years old living in the household. **(S_UNDR18)**

After the initial screening is completed, a single child is randomly selected from households with one or more children, ages 0-17.

The selected child is the subject of the National Survey of Children's Health Interview questions asked in **Sections 1 – 11** of the survey.

SECTION 1: Initial Demographics

1. Child's sex **(K1Q01)**
2. Respondent's relationship to the child **(K1Q02)**
3. What is the primary language spoken in your home? **(K1Q03)**

SECTION 2: Child's Health and Functional Status

1. In general, how would you describe [CHILD'S NAME] health? **(K2Q01)**
2. How would you describe the condition of [CHILD'S NAME] teeth? **(K2Q01_D)**
3. How tall is [CHILD'S NAME] now? **(K2Q02)**
4. How much does [CHILD'S NAME] weigh now? **(K2Q03)**
5. What was [CHILD'S NAME] birth weight? **(K2Q04)** *(ages 0-5 years)*
6. Does [CHILD'S NAME] currently need or use medicine prescribed by a doctor, other than vitamins? **(K2Q10-K2Q12)**
7. Does [CHILD'S NAME] need or use more medical care, mental health, or educational services than is usual for most children of the same age? **(K2Q13-K2Q15)**
8. Is [CHILD'S NAME] limited or prevented in any way in his/her ability to do the things most children of the same age can do? **(K2Q16-K2Q18)**
9. Does [CHILD'S NAME] need or get special therapy, such as physical, occupational, or speech therapy? **(K2Q19-K2Q21)**
10. Does [CHILD'S NAME] have any kind of emotional, developmental, or behavioral problem for which he/she needs treatment or counseling? **(K2Q22-K2Q23)**

    If YES to any of the above items 6-10 above, two follow up questions are asked:

    - Is this because of a medical, behavioral, or other health condition?
    - Has this condition lasted or is it expected to last for 12 months or longer?

11. Has a doctor, health professional, teacher, or school official ever told you [CHILD'S NAME] has a learning disability? **(K2Q30A)** *(ages 3-17 years)*
    - Does [CHILD'S NAME] currently have a learning disability? **(K2Q30B)**
    - Would you describe (his/her) learning disability as mild, moderate, or severe? **(K2Q30C)**

SECTION 2: Child's Health and Functional Status (continued)

12. For each condition, please tell me if a doctor or other health care provider ever told you that [CHILD'S NAME] had the condition, even if (he/she does not have the condition now. Has a doctor or health professional ever told you that [CHILD'S NAME] has any of the following conditions?

Ages 2-17

- Attention Deficit Disorder or Attention Deficit Hyperactive Disorder, that is ADD or ADHD* **(K2Q31A-K2Q31C)**
    - Is [CHILD'S NAME] currently taking medication for ADD or ADHD? (**K2Q31D)**
- Depression **(K2Q32A-K2Q32C)**
- Anxiety Problems **(K2Q33A-K2Q33C)**
- Behavior or conduct problems **(K2Q34A-K2Q34C)**
- Autism, Asperger's Disorder, pervasive development disorder, or other autism spectrum disorder **(K2Q35A-K2Q35C)**
- Any developmental delay **(K2Q36A-K2Q36C)**
- Stuttering, stammering, or other speech problems **(K2Q37A--K2Q37C)**

Ages 0-17

- Tourette Syndrome **(K2Q38A-K2Q38C)**
- Asthma **(K2Q40A-K2Q40C)**
    - Any difficulty with breathing or other respiratory problems? **(K2Q56G)**
- Diabetes **(K2Q41A-K2Q41C)**
- Epilepsy or seizure disorder **(K2Q42A-K2Q42C)**
- Hearing problems **(K2Q43A-K2Q43C)**
- Vision problems that can not be corrected with glasses or contact lenses? **(K2Q44A-K2Q44C)**
- Bone, joint, or muscle problems **(K2Q45A-K2Q45C)**
- A brain injury or concussion **(K2Q46A-K2Q46C)**

If YES to any of the items **K2Q31A-K2Q46A** above, two follow up questions are asked:

- Does [CHILD'S NAME] currently have condition? **(K2Q31B – K2Q46B)**
- Would you describe (his/her) condition as mild, moderate, or severe? **(K2Q31C – K2Q46C)**

13. For each condition, please tell me if a doctor or other health care provider told you that [CHILD'S NAME] had the condition at some time during the past 12 months, even if (he/she) does not have the condition now. During the past 12 months, have you been told by a doctor or other health professional that [CHILD'S NAME] had any of the following conditions?

- Hay fever or any kind of respiratory allergy **(K2Q47A)**
- Food or digestive allergy **(K2Q48A)**
- Eczema or any kind of skin allergy **(K2Q49A)**
- Frequent or severe headaches, including migraines **(K2Q50A)** *(ages 5 – 17 years)*
- Three or more ear infections **(K2Q51A)**

If YES to any of the items **K2Q47A-K2Q51A**, the following question is asked:

- Would you describe his/her health condition(s) as minor, moderate, or severe? **(K2Q47C-K2Q51C)**

14. To the best of your knowledge, has (he/she) had any of the following conditions within the past 6 months? *(ages 1-17 years)*

- A toothache **(K2Q52)**
- Decayed teeth or cavities **(K2Q53)**
- Broken teeth **(K2Q54)**
- Bleeding gums **(K2Q55)**

15. The following questions are asked for children identified as having special health care needs only. Do [CHILD'S NAME] medical, behavioral or other health conditions interfere with (his/her) ability to do any of the following things?

CSHCN ages 0-5

- Participate with other children **(K2Q60A)**
- Go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings? **(K2Q60B)**
- Make friends **(K2Q60C)**

CSHCN ages 6-17

- Attend school on a regular basis **(K2Q61A)**
- Participate in sports, clubs, or other organized activities **(K2Q61B)**
- Make friends **(K2Q61C)**

16. Has [CHILD'S NAME] received a tetanus booster shot, Td, or Tdap shot since (he/she) turned 11 years of age? **(K2Q81C)** *(ages 12-17 years)*

17. Has [CHILD'S NAME] ever received a meningitis shot? **(K2Q82)** *(ages 12-17 years)*

SECTION 2: Child's Health and Functional Status (continued)

18. The human papillomavirus is a common virus known to cause genital warts and some cancers, such as cervical cancer in women. A vaccine to prevent HPV infection is available and is called the cervical cancer vaccine. Has [CHILD'S NAME] ever received any HPV shots? **(K2Q83)** *(females ages 12-17 years)*
    - Please tell me how many HPV shots [CHILD'S NAME] has received. **(K2Q84)** *(females ages 12-17 years)*
19. Did a doctor or health care professional recommend that [CHILD'S NAME] receive HPV shots? **(K2Q85)** *(females ages 12-17 years)*

SECTION 3: Health Insurance Coverage

1. Does [CHILD'S NAME] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid? **(K3Q01)**
    - If YES, [Is that coverage/Is (he/she) insured by] Medicaid or the State Children's Health Insurance Program, S-CHIP? **(K3Q02)**
    - If YES, During the past 12 months, was there any time when (he/she) was not covered by ANY health insurance? **(K3Q03)**
    - If NO, During the past 12 months, was there anytime when (he/she) had health care coverage? **(K3Q04)**
2. The next four questions are asked for insured children only.
    - Does [CHILD'S NAME] health insurance offer benefits or cover services that meet (his/her) needs? **(K3Q20)**
    - Does [CHILD'S NAME] health insurance allow (him/her) to see the health care providers (he/she) needs? **(K3Q22)**
    - Not including health insurance premiums or costs that are covered by insurance, do you pay any money for [CHILD'S NAME] health care? **(K3Q21A)**
        - How often are these costs reasonable? **(K3Q21B)**

SECTION 4: Health Access and Utilization

1. Is there a place that [CHILD'S NAME] USUALLY goes when (he/she) is sick or you need advice about (his/her) health? **(K4Q01)**
    - Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place? **(K4Q02-K4Q03)**
2. A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as [CHILD'S NAME] personal doctor or nurse? **(K4Q04)**
3. During the past 12 months how many times did [CHILD'S NAME] see a doctor, nurse, or other health care provider for preventive medical care such as a physical exam or well-child checkup? **(K4Q20)**
4. During the past 12 months how many times did [CHILD'S NAME] see a dentist for preventive dental care, such as check-ups and dental cleanings? **(K4Q21)**
5. Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. During the past 12 months has [CHILD'S NAME] received any treatment or counseling from a mental health professional? **(K4Q22)** *(ages 2-17 years)*
6. During the past 12 months, has [CHILD'S NAME] taken any medication because of difficulties with (his/her) emotions, concentration, or behavior? **(K4Q23)** **asked only for children who are not taking medication for ADD/ADHD*
7. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. During the past 12 months, did [CHILD'S NAME] see a specialist? **(K4Q24)**
    - If NO, during the past 12 months, did you or a doctor think that (he/she) needed to see a specialist? **(K4Q25)**
    - If YES, During the past 12 months, how much of a problem, if any, was it to get the care from the specialists that [CHILD'S NAME] needed? **(K4Q26)**

1. Sometimes people have difficulty getting health care when they need it. By health care, I mean medical care as well as other kinds of care like dental care and mental health services. During the past 12 months, was there any time when [CHILD'S NAME] needed health care but it was delayed or not received? **(K4Q27)**
    - What type of care was delayed or not received? **(K4Q28)**

SECTION 5: Medical Home

1. During the past 12 months, did [CHILD'S NAME] need a referral to see any doctors or receive any services? **(K5Q10)**
   - Was getting referrals a big problem, small problem, or not a problem? **(K2Q11)**
2. Does anyone help you arrange or coordinate [CHILD'S NAME] care among the different doctors or services that (he/she) uses? **(K5Q20)** **asked for children who used more than two services*
3. During the past 12 months, have you felt that you could have used extra help arranging or coordinating [CHILD'S NAME] care among the different health care providers or services? **(K5Q21)** **asked for children who used more than two services*
   - If YES, during the past 12 months, how often did you get as much help as you wanted with arranging or coordinating [CHILD'S NAME] care? **(K5Q22)** **asked for children who used more than two services*
4. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [CHILD'S NAME] doctors and other health care providers? **(K5Q30)** **asked for children who used more than two services*
5. Do [CHILD'S NAME] doctor or other health care providers need to communicate with (his/her) child care providers, school, or other programs? **(K5Q31)**
   - Overall, are you very satisfied, somewhat satisfied, or very dissatisfied with that communication? **(K5Q32)**
6. During the past 12 months, how often did [CHILD'S NAME] doctors and other health care providers spend enough time with (him/her)? **(K5Q40)**
7. During the past 12 months, how often did [CHILD'S NAME] doctors and other health care providers listen carefully to you? **(K5Q41)**
8. When [CHILD'S NAME] is seen by doctors and other health care providers, how often are they sensitive to your family's values and customs? **(K5Q42)**
9. Information about a child's health or health care can include things such as the causes of any health problems, how to care for a child now, and what to expect in the future. During the past 12 months, how often did you get the specific information you needed from [CHILD'S NAME] doctors and other health care providers? **(K5Q43)**
10. During the past 12 months, how often did [CHILD'S NAME] doctors or other health care providers help you feel like a partner in (his/her) care? **(K5Q44)**
11. An interpreter is someone who repeats what one person says in a language used by another person. During the past 12 months, did you or [CHILD'S NAME] need an interpreter to help speak with (his/her) doctors or other health care providers? **(K5Q45)**
    - When you or [CHILD'S NAME] needed an interpreter, how often were you able to get someone other than a family member to help you speak with (his/her) doctors or other health care providers? **(K5Q46)**

SECTION 6: Early Childhood (0–5 years) *questions asked for children ages 0-5 years only

1. Do you have any concerns about [CHILD'S NAME] learning, development, or behavior? **(K6Q01)**
2. Are you concerned about how (he/she):
   - Talks and makes speech sounds? **(K6Q02)** *(ages 4 months – 5 years)*
   - Understands what you say? **(K6Q03)** *(ages 4 months – 5 years)*
   - Uses (his/her) hands and fingers to do things? **(K6Q04)** *(ages 4 months – 5 years)*
   - Uses (his/her) arms and legs? **(K6Q05)** *(ages 4 months – 5 years)*
   - Behaves? **(K6Q06)** *(ages 4 months – 5 years)*
   - Gets along with others? **(K6Q07)** *(ages 4 months – 5 years)*
   - Is learning to do things for (himself/herself) **(K6Q08)** *(ages 10 months to 5 years)*
   - Is learning pre-school or school skills? **(K6Q09)** *(ages 18 months - 5 years)*
3. During the past 12 months did [CHILD'S NAME] doctors or other health care providers ask if you have concerns about (his/her) learning, development, or behavior? **(K6Q10)**
   - If YES, during the past 12 months did (his/her) doctors or other health care providers give you specific information to address your concerns about (his/her) learning, development, or behavior? **(K6Q11)**

SECTION 6: Early Childhood (0–5 years) (continued)

4. Sometimes a child's doctor or other health care providers will ask parent to fill out a questionnaire at home or during their child's visit. During the past 12 months, did a doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about [CHILD'S NAME] development, communication, or social behaviors? **(K6Q12)** *(ages 10 months to 5 years)*
   - Did this questionnaire ask you about your concern or observations about how [CHILD'S NAME] talks or makes speech sounds **(K6Q13A)** *(ages 10-23 months only)*
   - Did this questionnaire ask you about how [CHILD'S NAME] interacts with you and others? **(K6Q13B)** *(ages 10-23 months only)*
   - Did this questionnaire ask you about your concerns or observations about word and phrases [CHILD'S NAME] uses and understands? **(K6Q14A)** *(ages 24-71 months only)*
   - Did this questionnaire ask you about your concerns or observations about how [CHILD'S NAME] behaves and gets along with you and others **(K6Q14B)** *(ages 24-71 months only)*
5. Does [CHILD'S NAME] have any developmental problems for which (he/she) has a written intervention plan called an Individual Family Services Plan (IFSP) or Individualized Education Program (IEP)? **(K6Q15)**
6. Does [CHILD'S NAME] receive care for at least 10 hours per week from someone not related to (him/her)? This could be a day care center, preschool, Head Start program, nanny, au pair, or any other non-relative. **(K6Q20)**
   - Was this care provided in your home, in someone else's home, or in a center such as school or day care facility? **(K6Q20B)**
7. Does [CHILD'S NAME] receive care for at least 10 hours per week from a relative other than (his/her) parents or guardians? **(K6Q21)**
   - If YES, Was this care provided in your home or somewhere else? **(K6Q22)**
8. During the past month, did you need child care for [CHILD'S NAME]? **(K6Q25A)**
   - Does [CHILD'S NAME] behavior limit your ability to find child care for (him/her)? **(K6Q25B)** *asked for CSHCN only
   - Does [CHILD'S NAME] health limit your ability to find child care for (him/her)? **(K6Q25C)** *asked for CSHCN only
   - During the past month, how many times have you had to make different arrangements for childcare at the last minute due to circumstances beyond your control? **(K6Q26)**
9. During the past 12 months, did you or anyone in the family have to quit a job, not take a job, or greatly change your job because of problems with child care for [CHILD'S NAME]? **(K6Q27)**
10. During the past 12 months, has [CHILD'S NAME] been injured and required medical attention? **(K6Q30)**
    - If YES, did the injury occur at home, at child-care, or some other place? **(K6Q31)**
11. Was [CHILD'S NAME] ever breastfed or fed breast milk? **(K6Q40)**
    - If YES, how old was [CHILD'S NAME] when [he/she] completely stopped breastfeeding or being fed breast milk? **(K6Q41)**
    - If YES, how old was [CHILD'S NAME] when [he/she] was first fed formula? **(K6Q42)**
    - This next question is about the first thing [CHILD'S NAME] was given other than breast milk or formula. Please include juice, cow's milk, sugar water, baby food, or anything else that [CHILD'S NAME] might have been given, even water. How old was [CHILD'S NAME] when [he/she] was first fed anything other than breast milk or formula? **(K6Q43)**
12. During the past week, how many days did you or other family members read to [CHILD'S NAME]? **(K6Q60)**
13. During the past week, how many days did you or other family members tell stories or sing songs to [CHILD'S NAME]? **(K6Q61)**
14. During the past week, how many days did [CHILD'S NAME] play with other children [his/her] age? **(K6Q63)**
15. During the past week, how many days did you or any family member take [CHILD'S NAME] on any kind of outing, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings? **(K6Q64)**
16. On an average weekday, about how much time does [CHILD'S NAME] usually watch TV or watch videos? **(K6Q65)**

SECTION 7: Middle Childhood and Adolescence (6-17 years) *questions asked for children ages 6-17 only

1. What kind of school is [CHILD'S NAME] currently enrolled in? **(K7Q01)**
   - If NOT ENROLLED, at any time during the past 12 months, was [CHILD'S NAME] enrolled in a public school, a private school, or home school? **(K7Q01F)**
2. During the past 12 months, about how many days did [CHILD'S NAME] miss school because of illness or injury? **(K7Q02)**
3. During the past 12 months, how many times has [CHILD'S NAME] school contacted you or another adult in your household about any problems [he/she] is having with school? **(K7Q04)**
4. Since starting kindergarten, has [he/she] repeated any grades? **(K7Q05)**
5. Does [CHILD'S NAME] have a health problem, condition, or disability for which [he/she] has a written intervention plan called an Individualized Education Program or IEP? **(K7Q11)**
6. During the past 12 months, was [CHILD'S NAME] on a sports team or did [he/she] take sports lessons after school or on the weekends? **(K7Q30)**
7. During the past 12 months, did [CHILD'S NAME] participate in any clubs or organizations after school or on weekends? **(K7Q31)**
   - If NO, during the past 12 months, did [he/she] participate in any other organized events or activities? **(K7Q32)**
8. During the past 12 months, how often did you attend events or activities that [CHILD'S NAME] participated in? Would you say never, sometimes, usually or always? **(K7Q33)**
9. Regarding [CHILD'S NAME] friends, would you say that you have met all of [his/her] friends, most of [his/her] friends, some of [his/her] friends, or none of [his/her] friends? **(K7Q34)**
10. Sometimes it is difficult to make arrangements to look after children all the time. During the past week, did [CHILD'S NAME] take care of [himself/herself] or stay alone without an adult or teenager, even for a small amount of time? **(K7Q35)**
    - If YES, during the past week, how many hours did [CHILD'S NAME] take care of [himself/herself]? **(K7Q36)**
11. During the past 12 months, how often has [CHILD'S NAME] been involved in any type of community service or volunteer work at school, church, or in the community? Would you say once a week or more, a few times a month, a few times a year, or never? **(K7Q37)**
12. During the past week, did [CHILD'S NAME] earn money from any work, including regular jobs as well as babysitting, cutting grass or other occasional work? **(K7Q38)**
    - If YES, during the past week, how many hours did [CHILD'S NAME] work for pay? **(K7Q39)**
13. During the past week, on how many nights did [CHILD'S NAME] get enough sleep for a child [his/her] age? **(K7Q40)**
14. During the past week, on how many days did [CHILD'S NAME] exercise, play a sport, or participate in physical activity for at least 20 minutes that made [him/her] sweat and breathe hard? **(K7Q41)**
15. On an average weekday, about how much time does [he/she] usually spend reading for pleasure? **(K7Q50)**
16. On an average weekday, about how much time does [CHILD'S NAME] use a computer for purposes other than schoolwork? **(K7Q51)**
17. On an average weekday, about how much time does [CHILD'S NAME] usually watch TV, watch videos or play video games? **(K7Q60)**
18. Are there family rules about what television programs [he/she] is allowed to watch? **(K7Q61)**
19. Is there a television in [CHILD'S NAME] bedroom? **(K7Q62)**
20. I am going to read a list of items that sometimes describe children. For each item, please tell me how often this was true for [CHILD'S NAME] during the past month:

- [He/She] argues too much. **(K7Q70)**
- [He/She] bullies or is cruel or mean to others. **(K7Q71)**
- [He/She] shows respect for teachers and neighbors. **(K7Q72)**
- [He/She] gets along well with other children. **(K7Q73)**
- [He/She] is disobedient. **(K7Q74)**
- [He/She] is stubborn, sullen, or irritable. **(K7Q75)**
- [He/She] tries to understand other people's feelings. **(K7Q76)**
- [He/She] tries to resolve conflicts with classmates, family, or friends. **(K7Q77)**
- [He/She] feels worthless or inferior. **(K7Q78)**
- [He/She] is unhappy, sad, or depressed. **(K7Q79)**
- [He/She] is withdrawn, and does not get involved with others. **(K7Q80)**
- [He/She] cares about doing well in school. **(K7Q82)**
- [He/She] does all required homework. **(K7Q83)**

SECTION 8: Family Functioning

1. About how often does [CHILD'S NAME] attend a religious service? **(K8Q12)**
2. During the past week, how many days did all the family members who live in the household eat a meal together? **(K8Q11)**
3. How well can you and [CHILD'S NAME] share ideas or talk about things that really matter? **(K8Q21)** *(ages 6-17 years)*
4. In general, how well do you feel you are coping with the day to day demands of (parenthood/raising children)? **(K8Q30)**
5. During the past month, how often have you felt [CHILD'S NAME] is much harder to care for than most other children (his/her) age? **(K8Q31)**
6. During the past month, how often have you felt (he/she) does things that really bother you a lot? **(K8Q32)**
7. During the past month, how often have you felt angry with (him/her)? **(K8Q34)**
8. Is there someone that you can turn to for day-to-day emotional help with [parenthood/raising children]? **(K8Q35)**

SECTION 9: Parental Health

1. Including the adults and all the children, how many people live in this household? **(K9Q00)**
2. Earlier you told me you are [CHILD'S NAME] (Mother/Father). Are you [CHILD'S NAME] biological, adoptive, step, or foster (mother/father)? **(K9Q10)**
3. Does [CHILD'S NAME] have any (other) parents, or people who act as (his/her) parents, living here? **(K9Q11)**
   - What is their relationship to [CHILD'S NAME]? **(K9Q12)**
4. Are you and [CHILD'S NAME] [FATHER TYPE] or [MOTHER TYPE] currently married or living together as partners? **(K9Q17A)**
5. Are you [MOTHER TYPE] currently married, separated, divorced, widowed, or never married? **(K9Q17B)** **asked only when the respondent is the mother*
6. Would you say that your relationship is completely happy, very happy, fairly happy, or not too happy? **(K9Q18)**
7. Would you say that, in general, ([CHILD'S NAME] [MOTHER TYPE]/your) health is excellent, very good, good, fair, or poor? **(K9Q20)**
8. Would you say that, in general, ([CHILD'S NAME] [FATHER TYPE]/your) health is excellent, very good, good, fair, or poor? **(K9Q21)**
9. Would you say that, in general, ([CHILD'S NAME] [MOTHER TYPE]/your) mental and emotional health is excellent, very good, good, fair, or poor? **(K9Q23)**
10. Would you say that, in general, ([CHILD'S NAME] [FATHER TYPE]/your) mental and emotional health is excellent, very good, good, fair, or poor? **(K9Q24)**
11. During the past week, on how many days did (you/[CHILD'S NAME] MOTHER TYPE) exercise, play sports, or participate in physical activity for at least 20 minutes that made [you/her] sweat and breathe hard? **(K9Q30)**
12. During the past week, on how many days did [FATHER TYPE] exercise, play sports, or participate in physical activity for at least 20 minutes that made him sweat and breathe hard? **(K9Q31)**
13. Does anyone living in your household use cigarettes, cigars, or pipe tobacco? **(K9Q40)**
    - Does anyone smoke inside the [CHILD'S NAME] home? **(K9Q41)**

SECTION 10: Neighborhood and Community Characteristics

1. Please tell me if the following places and things are available to children in your neighborhood, even if [CHILD'S NAME] does not actually use them:
   - Sidewalks or walking paths? **(K10Q11)**
   - A park or playground area? **(K10Q12)**
   - A recreation center, community center, or boys' or girls' club? **(K10Q13)**
   - A library or bookmobile? **(K10Q14)**
2. In your neighborhood, is there litter or garbage on the street or sidewalk? **(K10Q20)**
3. How about poorly kept or dilapidated housing? **(K10Q22)**

SECTION 10: Neighborhood and Community Characteristics (continued)

4. How about vandalism such as broken windows or graffiti? **(K10Q23)**
5. Now, for the next four questions, I am going to ask you how much you agree or disagree with each of these statements about your neighborhood or community:
   - "People in this neighborhood help each other out." **(K10Q30)**
   - "We watch out for each other's children in this neighborhood." **(K10Q31)**
   - "There are people I can count on in this neighborhood." **(K10Q32)**
   - "If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child." **(K10Q34)**
6. How often do you feel [CHILD'S NAME] is safe in your community or neighborhood? **(K10Q40)**
7. How often do you feel (he/she) is safe at school? **(K10Q41)**

SECTION 11: Additional Demographics

1. Is [CHILD'S NAME] of Hispanic or Latino origin? **(K11Q01)**
2. Is [CHILD'S NAME] White, Black or African American, American Indian, Alaska Native, Asian, or Native Hawaiian or other Pacific Islander? **(K11Q02)**
3. At any time during the past 12 months, did [CHILD'S NAME] receive services from any Indian Health Service hospital or clinic? **(K11Q03)** **asked only for American Indian or Alaska Native children*
4. What is the highest grade or year of school ([MOTHER TYPE/FATHER TYPE/OTHER] has) completed? **(K11Q20-K11Q21)**
5. Was [CHILD/ CHILD'S MOTHER/ CHILD'S FATHER] born in the United States? **(K11Q30-K11Q33)**
   - How long has [CHILD/ CHILD'S MOTHER/ CHILD'S FATHER] been in the United States? **(K11Q34A-K11Q37A)**
6. Was [CHILD'S NAME] adopted from another country? **(K11Q38)**
   - Prior to being adopted, was [CHILD'S NAME] in the legal custody of a state or county child welfare agency in the United States? That is, was [CHILD'S NAME] in the U.S. foster care system? **(K11Q40)**
   - Has [CHILD'S NAME] adoption been finalized? **(K11Q41)**
7. How many times has [CHILD'S NAME] ever moved to a new address? **(K11Q43)**
8. Was anyone in the household employed at least 50 weeks out of the 52 weeks? **(K11Q50)**
9. At any time during the past 12 months, even for one month, did anyone in this household receive any cash assistance from a state or a county welfare program? **(K11Q60)**
10. During the past 12 months, did ([CHILD'S NAME]/any child in the household) receive Food Stamps? **(K11Q61)**
11. During the past 12 months, did ([CHILD'S NAME]/any child in the household) receive free or reduced-cost breakfasts or lunches at school? **(K11Q62)**

Measure # 52: Mental Health Professional HIV/AIDS Point Prevalence and Treatment Experiences Survey Part II

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Measure # 53: Cardiac Rehabilitation Patient Referral from an Inpatient Setting

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Measure # 54: Cardiac Rehabilitation Patient Referral from an Outpatient Setting

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Measure # 55: Patients with a Transient Ischemic Event ER Visit that had a Follow Up Office Visit

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Measure # 56: Biopsy Follow Up

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Measure # 57: Reconciled Medication List Received by Discharged Patients

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Measure # 58: Transition Record with Specified Elements Received by Discharged Patients (Inpatient Discharges)

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Measure # 59: Timely Transmission of Transition Record

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Measure # 60: Transition Record with Specified Elements Received by Discharged Patients (Emergency Department Discharges)

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Measure # 61: Melanoma Continuity of Care – Recall System

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