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.

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.

Updated December 12, 2011

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

Contact Information:

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

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Please complete the following information about you and your organization. This information will not be disclosed to anyone besides the ICIC/IHI team. We would like to get your phone number and e-mail address in the event that we need to contact you/your team in the future. Please also indicate the names of persons (e.g., team members) who complete the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.

Your name:	**Date:** ________/________/________ Month Day Year
Organization & Address:	**Names of other persons completing the survey with you:** 1. 2. 3.
Your phone number: (______) __ __ __ - __ __ __ __	**Your e-mail address:**

This survey is designed to help systems and provider practices move toward the "state-of-the-art" in managing chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

   Please provide name and type of site (e.g., Group Health Cooperative/Plan) ________________________________

2. **Answer each question** regarding how your organization is doing with respect to one disease or condition.

   Please specify condition ________________________________

3. For each row, **circle the point value** that best describes the level of care that currently exists in the site and condition you chose. The rows in this form present key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The higher point values indicate that the actions described in that box are more fully implemented.

4. **Sum the points in each section** (e.g., total part 1 score), calculate the average score (e.g., total part 1 score / # of questions), and enter these scores in the space provided at the end of each section. Then sum all of the section scores and complete the average score for the program as a whole by dividing this by 6.

For more information about how to complete the survey, please contact:

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Improving Chronic Illness Care
A National Program of the Robert Wood Johnson Foundation
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Seattle, WA 98101-1448

Assessment of Chronic Illness Care, Version 3.5

Part 1: Organization of the Healthcare Delivery System. Chronic illness management programs can be more effective if the overall system (organization) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.

Components	Level D	Level C	Level B	Level A
Overall Organizational Leadership in Chronic Illness Care	…does not exist or there is a little interest.	…is reflected in vision statements and business plans, but no resources are specifically earmarked to execute the work.	…is reflected by senior leadership and specific dedicated resources (dollars and personnel).	…is part of the system's long term planning strategy, receive necessary resources, and specific people are held accountable.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Organizational Goals for Chronic Care	…do not exist or are limited to one condition.	…exist but are not actively reviewed.	…are measurable and reviewed.	…are measurable, reviewed routinely, and are incorporated into plans for improvement.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Improvement Strategy for Chronic Illness Care	…is ad hoc and not organized or supported consistently.	…utilizes ad hoc approaches for targeted problems as they emerge.	…utilizes a proven improvement strategy for targeted problems.	…includes a proven improvement strategy and uses it proactively in meeting organizational goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Incentives and Regulations for Chronic Illness Care	…are not used to influence clinical performance goals.	…are used to influence utilization and costs of chronic illness care.	…are used to support patient care goals.	…are used to motivate and empower providers to support patient care goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Senior Leaders	…discourage enrollment of the chronically ill.	…do not make improvements to chronic illness care a priority.	…encourage improvement efforts in chronic care.	…visibly participate in improvement efforts in chronic care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Benefits	…discourage patient self-management or system changes.	…neither encourage nor discourage patient self-management or system changes.	…encourage patient self-management or system changes.	…are specifically designed to promote better chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Health Care Organization Score ________ Average Score (Health Care Org. Score / 6) _________

Part 2: Community Linkages. Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of chronic illness.

Components	Level D	Level C	Level B	Level A
Linking Patients to Outside Resources	…is not done systematically.	…is limited to a list of identified community resources in an accessible format.	…is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources.	… is accomplished through active coordination between the health system, community service agencies and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Partnerships with Community Organizations	…do not exist.	…are being considered but have not yet been implemented.	…are formed to develop supportive programs and policies.	…are actively sought to develop formal supportive programs and policies across the entire system.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Regional Health Plans	…do not coordinate chronic illness guidelines, measures or care resources at the practice level.	…would consider some degree of coordination of guidelines, measures or care resources at the practice level but have not yet implemented changes.	…currently coordinate guidelines, measures or care resources in one or two chronic illness areas.	…currently coordinate chronic illness guidelines, measures and resources at the practice level for most chronic illnesses.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Community Linkages Score ___________

Average Score (Community Linkages Score / 3) _________

Part 3: Practice Level. Several components that manifest themselves at the level of the individual provider practice (e.g. individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

Part 3a: Self-Management Support. Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.

Components	**Level D**	**Level C**	**Level B**	**Level A**
Assessment and Documentation of Self-Management Needs and Activities	…are not done.	…are expected.	…are completed in a standardized manner.	…are regularly assessed and recorded in standardized form linked to a treatment plan available to practice and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Self-Management Support	…is limited to the distribution of information (pamphlets, booklets).	…is available by referral to self-management classes or educators.	…is provided by trained clinical educators who are designated to do self-management support, affiliated with each practice, and see patients on referral.	…is provided by clinical educators affiliated with each practice, trained in patient empowerment and problem-solving methodologies, and see most patients with chronic illness.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Addressing Concerns of Patients and Families	…is not consistently done.	…is provided for specific patients and families through referral.	…is encouraged, and peer support, groups, and mentoring programs are available.	…is an integral part of care and includes systematic assessment and routine involvement in peer support, groups or mentoring programs.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Effective Behavior Change Interventions and Peer Support	…are not available.	…are limited to the distribution of pamphlets, booklets or other written information.	…are available only by referral to specialized centers staffed by trained personnel.	…are readily available and an integral part of routine care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Self-Management Score_______ Average Score (Self Management Score / 4) _______

Part 3b: Decision Support. Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for patients--decision support. This includes evidence-based practice guidelines or protocols, specialty consultation, provider education, and activating patients to make provider teams aware of effective therapies.

Components	**Level D**	**Level C**	**Level B**	**Level A**
Evidence-Based Guidelines	…are not available.	…are available but are not integrated into care delivery.	…are available and supported by provider education.	…are available, supported by provider education and integrated into care through reminders and other proven provider behavior change methods.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Involvement of Specialists in Improving Primary Care	…is primarily through traditional referral.	…is achieved through specialist leadership to enhance the capacity of the overall system to routinely implement guidelines.	…includes specialist leadership and designated specialists who provide primary care team training.	…includes specialist leadership and specialist involvement in improving the care of primary care patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Provider Education for Chronic Illness Care	…is provided sporadically.	…is provided systematically through traditional methods.	…is provided using optimal methods (e.g. academic detailing).	…includes training all practice teams in chronic illness care methods such as population-based management, and self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in achieving guideline adherence.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Decision Support Score_______ Average Score (Decision Support Score / 4) _______

Part 3c: Delivery System Design. Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organization of practice that impact provision of care.

Components	**Level D**	**Level C**	**Level B**	**Level A**
Practice Team Functioning	…is not addressed.	…is addressed by assuring the availability of individuals with appropriate training in key elements of chronic illness care.	…is assured by regular team meetings to address guidelines, roles and accountability, and problems in chronic illness care.	…is assured by teams who meet regularly and have clearly defined roles including patient self-management education, proactive follow-up, and resource coordination and other skills in chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Practice Team Leadership	…is not recognized locally or by the system.	…is assumed by the organization to reside in specific organizational roles.	…is assured by the appointment of a team leader but the role in chronic illness is not defined.	…is guaranteed by the appointment of a team leader who assures that roles and responsibilities for chronic illness care are clearly defined.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Appointment System	…can be used to schedule acute care visits, follow-up and preventive visits.	…assures scheduled follow-up with chronically ill patients.	…are flexible and can accommodate innovations such as customized visit length or group visits.	…includes organization of care that facilitates the patient seeing multiple providers in a single visit.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Follow-up	…is scheduled by patients or providers in an ad hoc fashion.	…is scheduled by the practice in accordance with guidelines.	…is assured by the practice team by monitoring patient utilization.	…is customized to patient needs, varies in intensity and methodology (phone, in person, email) and assures guideline follow-up.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Planned Visits for Chronic Illness Care	…are not used.	…are occasionally used for complicated patients.	…are an option for interested patients.	…are used for all patients and include regular assessment, preventive interventions and attention to self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Continuity of Care	…is not a priority.	…depends on written communication between primary care providers and specialists, case managers or disease management	…between primary care providers and specialists and other relevant providers is a priority but not implemented systematically.	…is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant

Components	Level D			Level C			Level B			Level A		
				companies.						groups.		
Score	0	1	2	3	4	5	6	7	8	9	10	11

(From Previous Page)

Total Delivery System Design Score_______ Average Score (Delivery System Design Score / 6) _______

Part 3d: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches.[7, 8]

Components	Level D			Level C			Level B			Level A		
Registry (list of patients with specific conditions)	…is not available.			…includes name, diagnosis, contact information and date of last contact either on paper or in a computer database.			…allows queries to sort sub-populations by clinical priorities.			…is tied to guidelines which provide prompts and reminders about needed services.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Reminders to Providers	…are not available.			… include general notification of the existence of a chronic illness, but does not describe needed services at time of encounter.			…includes indications of needed service for populations of patients through periodic reporting.			…includes specific information for the team about guideline adherence at the time of individual patient encounters.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Feedback	…is not available or is non-specific to the team.			…is provided at infrequent intervals and is delivered impersonally.			…occurs at frequent enough intervals to monitor performance and is specific to the team's population.			…is timely, specific to the team, routine and personally delivered by a respected opinion leader to improve team performance.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Information about Relevant Subgroups of Patients Needing Services	…is not available.			…can only be obtained with special efforts or additional programming.			…can be obtained upon request but is not routinely available.			…is provided routinely to providers to help them deliver planned care.		
Score	0	1	2	3	4	5	6	7	8	9	10	11
Patient Treatment Plans	…are not expected.			…are achieved through a standardized approach.			…are established collaboratively and include self management as well as clinical goals.			…are established collaborative an include self management as well as clinical management. Follow-up occurs and guides care at every point of service.		
Score	0	1	2	3	4	5	6	7	8	9	10	11

Total Clinical Information System Score_______ Average Score (Clinical Information System Score / 5) ________

Integration of Chronic Care Model Components. Effective systems of care integrate and combine all elements of the Chronic Care Model; e.g., linking patients' self-management goals to information systems/registries.

Components	Little support	Basic support	Good support	Full support
Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in achieving guideline adherence.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Information Systems/Registries	…do not include patient self-management goals.	…include results of patient assessments (e.g., functional status rating; readiness to engage in self-management activities), but no goals.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team/provider and patient.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team and patient; and prompt reminders to the patient and/or provider about follow-up and periodic re-evaluation of goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Community Programs	…do not provide feedback to the health care system/clinic about patients' progress in their programs.	…provide sporadic feedback at joint meetings between the community and health care system about patients' progress in their programs.	…provide regular feedback to the health care system/clinic using formal mechanisms (e.g., Internet progress report) about patients' progress.	…provide regular feedback to the health care system about patients' progress that requires input from patients that is then used to modify programs to better meet the needs of patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Organizational Planning for Chronic Illness Care	…does not involve a population-based approach.	…uses data from information systems to plan care.	…uses data from information systems to proactively plan population-based care, including the development of self-management programs and partnerships with community resources.	…uses systematic data and input from practice teams to proactively plan population-based care, including the development of self-management programs and community partnerships, that include a built-in evaluation plan to determine success over time.
			6 7 8	

Components	Little support	Basic support	Good support	Full support
Score	0 1 2	3 4 5		9 10 11
Routine follow-up for appointments, patient assessments and goal planning	…is not ensured. 0 1 2	is sporadically done, usually for appointments only. 3 4 5	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager). 6 7 8	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager) who uses the registry and other prompts to coordinate with patients and the entire practice team. 9 10 11
Guidelines for chronic illness care	…are not shared with patients. 0 1 2	…are given to patients who express a specific interest in self-management of their condition. 3 4 5	…are provided for all patients to help them develop effective self-management or behavior modification programs, and identify when they should see a provider. 6 7 8	…are reviewed by the practice team with the patient to devise a self-management or behavior modification program consistent with the guidelines that takes into account patient's goals and readiness to change. 9 10 11

Total Integration Score (SUM items): __________ ➢ **Average Score (Integration Score/6) =** __________

Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: ____

____

Scoring Summary
(bring forward scoring at end of each section to this page)

Total Org. of Health Care System Score _______

Total Community Linkages Score _______

Total Self-Management Score _______

Total Decision Support Score _______

Total Delivery System Design Score _______

Total Clinical Information System Score _______

Total Integration Score _______

Overall Total Program Score (Sum of all scores)

Average Program Score (Total Program /7) ______

______

What does it mean?

The ACIC is organized such that the highest “score” (an “11”) on any individual item, subscale, or the overall score (an average of the six ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a “0”, which corresponds to limited support for chronic illness care. The interpretation guidelines are as follows:

Between “0” and “2” = limited support for chronic illness care
Between “3” and “5” = basic support for chronic illness care
Between “6” and “8” = reasonably good support for chronic illness care
Between “9” and “11” = fully developed chronic illness care

It is fairly typical for teams to begin a collaborative with average scores below “5” on some (or all) areas the ACIC. After all, if everyone was providing optimal care for chronic illness, there would be no need for a chronic illness collaborative or other quality improvement programs. It is also common for teams to initially believe they are providing better care for chronic illness than they actually are. As you progress in the Collaborative, you will become more familiar with what an effective system of care involves. You may even notice your ACIC scores “declining” even though you have made improvements; this is most likely the result of your better understanding of what a good system of care looks like. Over time, as your understanding of good care increases and you continue to implement effective practice changes, you should see overall improvement on your ACIC scores.

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

Contact Information:

- Contact information unavailable.

Copyright Details:

- To request a copy of the measure instrument and/or obtain permission to use it, go to: http://www.rand.org/health/projects/acove/pubs/acove2.html.

Measure # 3: Coleman Measures of Care Coordination

Contact Information:

- For questions regarding this measure and for permission to use it, contact:
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  13199 East Montview Blvd, Suite 400
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  www.caretransitions.org

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Additional Notes:

- The Coleman Measures of Care Coordination includes an adaptation of a telephone self-report survey published originally in: Flocke, SA. J Fam Pract 1997; 45(1):64-75. 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.

Coleman Measures of Care Coordination

The following question items were taken from the source article: Coleman EA, Eilertsen TB, Magid DJ, et al. The association between care coordination and emergency department use in older managed care enrollees. Int J Integr Care 2002; 2:1-11.

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.

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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 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

TABLE OF CONTENTS

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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- 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**:
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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 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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- **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.

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.

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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.

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

Instructions for Front Cover

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>
> **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.
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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

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

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File name: 353a-4_ChildPrim_Eng_4pt_V1.doc
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- **Renumber** the supplemental item and **ALL** subsequent items so that they are consecutive.

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)

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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)		Time Spent*							Staff	Clinical Comp.	Initials
						Prevented	Occurred	1	2	3	4	5	6	7			

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 e. Hospital/Clinic
   b. Parent/family f. Payer
   c. School g. Voc. / training
   d. Agency h. Pharmacy
2. **Electronic (E-Mail) Contact with:**
   a. Patient e. Hospital/Clinic
   b. Parent f. Payer
   c. School g. Voc. / training
   d. Agency h. Pharmacy
3. **Contact with Consultant**
   a. Telephone c. Letter
   b. Meeting 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 c. Letter
    b. Meeting 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** (chose **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

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

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Client Perception of Coordination Questionnaire (CPCQ)

The following instrument items were identified by contacting the measure developer. Item content abbreviation is available in the following article: McGuiness C, Sibthorpe B. Development and initial validation of a measure of coordination of health care. Int J Qual Health Care 2003; 15(4):309-18.

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 24

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 – i.e., 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 Scale (CPS) – Nurse Scale

Contact Information:

- Contact information unavailable.

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

Contact Information:

- Contact information unavailable.

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

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

The items mapped in the *Atlas* are from Tables 1 and 2 of the source article: Katz SJ, Hawley ST, Morrow M, et al. Coordinating cancer care: patient and practice management processes among surgeons who treat breast cancer. Med Care 2010; 48(1):45-51. The measure developer recommended a more complete version, which follows this page. The numbering of that instrument is different to that in the *Atlas*, therefore we designed the table below to serve as a crosswalk and demonstrate which instrument items were mapped in the *Atlas* profile.

Crosswalk between the items mapped in the *Care Coordination Measures Atlas* and the Surgeon Survey instrument included in Appendix IV.		
Section	Item as numbered in the instrument provided by the measure developer	Instrument numbering as mapped in the *Atlas* measure mapping table and profile
B. Exchange of Medical Information		
	B3	1
	B4	2
	B5	3
	B6	4
	B7	5
	B8	6
C. Patient Services		
	C7	7
	C8	8
	C10	9
	C9	10
	C11	11
A. Your Practice Setting		
	A18a	12
	A18b	13
	A18c	14
	A24	15
	A25	16
	A26	17

Study ID # ____________________

Surgeon Perspectives about Breast Cancer Treatment Practices

Conducted by:

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University of Michigan

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This study is funded by a grant from the National Institutes of Health and has been approved by the Institutional Review Boards of University of Southern California and University of Michigan.

Version date: 4/18/07

Section A: Your Practice Setting

A1. How many surgeons who treat patients with breast cancer work in your practice (counting yourself)? ______

A2. How many medical oncologists who treat patients with breast cancer work in your practice? ______

A3. How many radiation oncologists who treat patients with breast cancer work in your practice? ______

A4. How many plastic surgeons who treat patients with breast cancer work in your practice? ______

A5. Does your practice have surgical residents?

☐1 Yes ☐2 No

A6. Does your practice have surgical or breast oncology fellows?

☐1 Yes ☐2 No

A7. Does your practice employ nurse practitioners or physician assistants who see patients with cancer?

☐1 Yes ☐2 No

A8. Does your practice have access to social workers who see patients with cancer?

☐1 Yes ☐2 No

A9. Does your practice have access to nutritionists who see patients with cancer?

☐1 Yes ☐2 No

A10. Is your practice affiliated with a University?

☐1 Yes ☐2 No

A11. Do you practice in a hospital that has a cancer program that is approved by the American College of Surgeons?

☐1 Yes ☐2 No ☐3 I don't know

A12. Do you practice in a hospital that is an NCI designated cancer center?

☐1 Yes ☐2 No ☐3 I don't know

A13. How many of your work hours are devoted to patient care (including surgery) per week?

☐1 up to 20 hours
☐2 21 to 30 hours
☐3 31 to 40 hours
☐4 41 to 60 hours
☐5 more than 60 hours

A14. Please indicate the approximate percentage (%) of your patient practice in the past 12 months devoted to the types of patients below:

a. _____ % Breast cancer patients

b. _____ % Other (non-breast) oncology patients

c. _____ % Non-oncology patients

100% Total for the past 12 months

A15. How many patients who were newly diagnosed with breast cancer have you treated in the past 12 months?

- ☐1 fewer than 10
- ☐2 11 - 20
- ☐3 21 - 50
- ☐4 51 - 100
- ☐5 more than 100

A16. What percentage of these patients came to you for a second opinion (e.g. after first consulting with another surgeon about their treatment options)?

- ☐1 fewer than 10%
- ☐2 10% - 25%
- ☐3 26% - 50%
- ☐4 more than 50%

A17. In the past 12 months, did you have access to a meeting (e.g. a tumor board) where different specialists discussed the treatment plan for your patients with cancer prior to final treatment decisions?

- ☐1 No
- ☐2 Yes → a. How frequently was the meeting held?
  - ☐1 Weekly
  - ☐2 Twice a month
  - ☐3 Once a month
  - ☐4 Other (please specify) ________________________________

  b. What percentage of patients discussed in these meetings had breast cancer? _______%

A18. In the past 12 months…

a. …did you have access to an online medical record system for clinical test results?

☐1 Yes ☐2 No

b. …did you have access to an online medical record system for physician notes?

☐1 Yes ☐2 No

c. …did you have access to an online patient orders entry system?

☐1 Yes ☐2 No

A19. In the past 12 months, did your practice regularly arrange same-day appointments for new patients with breast cancer to meet with different clinician specialists prior to definitive surgery?

☐1 Yes ☐2 No

A20. What is the average wait, after completion of the workup, to schedule surgery for your patients in your primary practice?

☐1 7 days or less

☐2 8 - 21 days

☐3 more than 3 weeks

☐4 Other (please specify) _____________________

A21. Approximately what percentage of your patients in the past 12 months had Medicaid? _____%

A22. Does your practice have interpreters available for non-English speaking patients?

☐1 Yes ☐2 No

A23. Has your practice developed a website tailored to patients with breast cancer?

☐1 Yes ☐2 No

A24. Does your practice collect information about patients for purposes of research or quality of care?

☐1 Yes ☐2 No

A25. Does your practice provide feedback to its clinicians about meeting clinical management standards?

☐1 Yes ☐2 No

A26. Does your practice participate in a regional or national network that is used to examine variations in treatment?

☐1 Yes ☐2 No

Section B: Exchange of Medical Information

For the following questions, please mark the answer that best describes your experience.

Thinking about your patients in the past 12 months, <u>with newly diagnosed breast cancer</u>, for how many. . .	**Few or Almost None**	**About One Third**	**About Half**	**About Two Thirds**	**Almost All**
B1. … did you have pathology reports at the time of your first consultation?.	☐1	☐2	☐3	☐4	☐5
B2. … did you have mammography reports at the time of your first consultation?.	☐1	☐2	☐3	☐4	☐5
B3. … did you discuss the treatment plan with a medical oncologist <u>prior to</u> the definitive surgery?.	☐1	☐2	☐3	☐4	☐5
B4. … did you discuss the treatment plan with a radiation oncologist <u>prior to</u> the definitive surgery?.	☐1	☐2	☐3	☐4	☐5
B5. … did you discuss the treatment plan with a plastic surgeon <u>prior to</u> the definitive surgery?.	☐1	☐2	☐3	☐4	☐5

Thinking about your patients in the past 12 months, with newly diagnosed breast cancer, <u>who brought you outside test results,</u> for how many. . .	**Few or Almost None**	**About One Third**	**About Half**	**About Two Thirds**	**Almost All**
B6. …did you have pathology specimens that were collected by another provider reviewed again by your pathologist? . . .	☐1	☐2	☐3	☐4	☐5
B7. … did you have mammogram images that were taken at another institution reviewed again by your radiologist?. . . .	☐1	☐2	☐3	☐4	☐5
B8. … did you repeat the mammogram images that were brought from another institution?.	☐1	☐2	☐3	☐4	☐5

Section C: Patient Services

For the following questions, please mark the answer that best describes your practice.

How many of your <u>patients</u> in the past 12 months <u>with newly diagnosed breast cancer</u>. . .	**Few or Almost None**	**About One Third**	**About Half**	**About Two Thirds**	**Almost All**
C1. … consulted with a medical oncologist <u>prior to</u> the definitive surgery?.					
C2. … consulted with a radiation oncologist <u>prior to</u> the definitive surgery?.	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C3. … consulted with a plastic surgeon <u>prior to</u> the definitive surgery?.					
C4. … met with a social worker <u>prior to</u> the definitive surgery?.	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C5. … met with a nurse practitioner or physician's assistant <u>prior to</u> the definitive surgery?.					
C6. … met with a nutritionist <u>prior to</u> the definitive surgery?.	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C7. ... attended a presentation about breast cancer treatment, organized by your practice, <u>prior to</u> the definitive surgery?. . . .					
C8. … viewed a video, made available through your practice, about treatment issues for breast cancer <u>prior to</u> the definitive surgery?	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C9. … attended a patient support group organized by your practice?.	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C10. … were referred to a specific website by your practice, that is tailored to patients with breast cancer?.	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
C11. …talked to other patients with breast cancer, arranged by your practice?					

Section D: Challenges in Your Practice

For the following questions, please mark the answer that best describes your experience.

Thinking about your patients in the past 12 months, with newly diagnosed breast cancer, how big of a problem was…	**No problem**		**Somewhat of a problem**		**A big problem**
D1. … getting mammography reports for your first consultation?	☐1	☐2	☐3	☐4	☐5
D2. … getting pathology reports for your first consultation?	☐1	☐2	☐3	☐4	☐5
D3. … getting pathology specimens that were collected by another institution reviewed by your pathologist?	☐1	☐2	☐3	☐4	☐5
D4. ... getting mammogram images that were taken at another institution reviewed by your radiologist?	☐1	☐2	☐3	☐4	☐5
D5. … arranging to discuss your patient’s treatment plan at a tumor board prior to the definitive surgery?	☐1	☐2	☐3	☐4	☐5
D6. ... arranging to discuss the treatment plan with a medical oncologist prior to the definitive surgery?	☐1	☐2	☐3	☐4	☐5
D7. ... arranging to discuss the treatment plan with a radiation oncologist prior to the definitive surgery?	☐1	☐2	☐3	☐4	☐5
D8. ... arranging to discuss the treatment plan with a plastic surgeon prior to the definitive surgery?	☐1	☐2	☐3	☐4	☐5
D9. ... arranging to discuss the treatment plan with a medical oncologist after the definitive surgery?	☐1	☐2	☐3	☐4	☐5
D10. ... arranging for your patients to meet with practitioners such as a social worker or counselor?	☐1	☐2	☐3	☐4	☐5
D11. … arranging for your patients to meet with other patients with breast cancer? . .	☐1	☐2	☐3	☐4	☐5

Section E: Practice Patterns

Please read the brief scenarios below and answer the questions that follow. There are no clear right answers. We are interested in your opinions about some challenging treatment decisions.

Scenario #1

A 60 year old woman presents with a 3 cm mass in the upper outer quadrant of a large breast. A core biopsy shows grade 3 infiltrating ductal carcinoma, ER/PR negative, HER-2 negative. The patient has no contraindications to either surgical option and requests your recommendation.

E1. Please circle the ONE letter below that best describes which treatment you would recommend and how strongly you would recommend it.

A Strongly	B Moderately	C Weakly	D Strongly	E Moderately	F Weakly
Mastectomy			**Lumpectomy with radiation**		

The patient receives mastectomy and is found to have a 3.5 cm tumor with metastases in 3 of 20 nodes.

E2. Please circle the ONE letter below that best describes which treatment option you would recommend, in addition to chemotherapy, and how strongly you would recommend it.

A Strongly	B Moderately	C Weakly	D Strongly	E Moderately	F Weakly
No further treatment			**Radiation therapy to the chest wall and nodal fields**		

Scenario #2

A 60 year old woman presents with a 0.8 cm mass in the upper outer quadrant of a large breast. A core biopsy shows grade 3 infiltrating ductal carcinoma, ER/PR negative, HER-2 negative. The patient has no contraindications to either surgical option and requests your recommendation.

E3. Please circle the ONE letter below which best describes which treatment you would recommend, and how strongly you would recommend it?

A Strongly	B Moderately	C Weakly	D Strongly	E Moderately	F Weakly
Mastectomy			**Lumpectomy with radiation**		

The patient received lumpectomy with radiation and sentinel node biopsy.

E4. What negative margin width precludes the need for re-excision?
(Please mark ONE box):

☐1 tumor cells not touching the ink

☐2 greater than 1-2 mm

☐3 greater than 5 mm

☐4 greater than 1 cm

Intraoperative exam of a sentinel node is negative. Final pathology report describes a 1.6 cm grade 3 infiltrating ductal carcinoma, ER/PR negative, HER-2 negative with widely negative margin. The one sentinel node removed has a 0.6mm metastases detected by H&E staining.

E5. Please circle the ONE letter below that best describes which approach you would recommend and how strongly you would recommend it.

A Strongly	B Moderately	C Weakly	D Strongly	E Moderately	F Weakly
No further axillary surgery			**Axillary dissection**		

Scenario #3

A 60 year old woman presents with a cluster of calcifications in the upper outer quadrant of the right breast on a screening mammogram. A core biopsy shows DCIS. Needle localization and excision demonstrate a 1.4 cm, grade 2 DCIS, ER positive tumor. The closest margin is 5 mm. The patient requests your treatment recommendation.

E6. Please circle the ONE letter below which best describes which treatment option you would recommend and how strongly you would recommend it.

A	B	C	D	E	F
Strongly	Moderately	Weakly	Strongly	Moderately	Weakly
Tamoxifen			**No tamoxifen**		

E7. Please circle the ONE letter below which best describes which treatment option you would recommend and how strongly you would recommend it.

A	B	C	D	E	F
Strongly	Moderately	Weakly	Strongly	Moderately	Weakly
Radiation therapy			**No radiation therapy**		

The patient opts for radiation therapy.

E8. Please circle the ONE letter below which best describes the radiation treatment you would recommend (outside of a clinical trial) and how strongly you would recommend it.

A	B	C	D	E	F
Strongly	Moderately	Weakly	Strongly	Moderately	Weakly
Whole breast radiation			**Partial breast radiation**		

E9. What negative margin width precludes the need for re- excision? (Please mark ONE box):

☐1 tumor cells not touching the ink

☐2 greater than 1-2 mm

☐3 greater than 5 mm

☐4 greater than 1 cm

E10. If the patient did not receive radiation, what negative margin width precludes the need for re- excision? (Please mark ONE box):

☐1 tumor cells not touching the ink

☐2 greater than 1-2 mm

☐3 greater than 5 mm

☐4 greater than 1 cm

Scenario #4

A 60 year old woman presents with a 4cm mass in the outer upper quadrant of a small breast. The axilla is clinically negative. The mammogram shows a single mass. The core biopsy shows grade 3 infiltrating ductal carcinoma, ER/PR negative, HER-2 negative. The patient requests your treatment recommendation.

E11. Please circle the ONE letter below which best describes which treatment option you would recommend, and how strongly you would recommend it.

A	B	C	D	E	F
Strongly	Moderately	Weakly	Strongly	Moderately	Weakly
Mastectomy with or without reconstruction			**Referral for preoperative chemotherapy to allow lumpectomy**		

The patient receives chemotherapy and the mass in the breast decreases to 1 cm in size. The axilla remains clinically negative.

E12. Please circle the ONE letter below that best describes which approach you would recommend and how strongly you would recommend it.

A	B	C	D	E	F
Strongly	Moderately	Weakly	Strongly	Moderately	Weakly
Sentinel node biopsy			**Axillary dissection**		

Section F: A Few More Questions About You

F1. How many years have you been in practice since completing your training? ________

F2. At how many hospitals do you perform surgery?

- ☐1 1
- ☐2 2
- ☐3 3 or more

F3. What was your age on your last birthday? _______________

F4. What is your gender? ☐1 Male ☐2 Female

F5. Are you Spanish/Hispanic/Latino? ☐1 Yes ☐2 No

F6. Which of the following best describes your race? **Please mark ALL that apply.**

- ☐1 White
- ☐2 Black, African-American
- ☐3 American Indian or Alaska Native
- ☐4 Asian or Pacific Islander
- ☐5 Some other race (Please specify) ____________________________

Thank you very much for completing this survey!

If you would like us to send you a summary of the study results at the end of the project, please mark here: ☐

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

Contact Information:

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

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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
Please register to use (no fee required) at: www.caretransitions.org

Measure # 9b: Care Transitions Measure (CTM-15)

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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**

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**

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**

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

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Assessment of Care for Chronic Conditions

Staying healthy can be difficult when you have a chronic condition. We would like to learn about the type of help with your condition you get from your health care team. This might include your regular doctor, his or her nurse, or physician's assistant who treats your illness. Your answers will be kept confidential and will not be shared with your physician or clinic.

Over the past 6 months, when I received care for my chronic conditions, I was:

	None of the time	A Little of the Time	Some of the Time	Most of the Time	Always
B1. Asked for my ideas when we made a treatment plan.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B2. Given choices about treatment to think about.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B3. Asked to talk about any problems with my medicines or their effects.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B4. Given a written list of things I should do to improve my health.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B5. Satisfied that my care was well organized.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B6. Shown how what I did to take care of myself influenced my condition.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B7. Asked to talk about my goals in caring for my condition.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B8. Helped to set specific goals to improve my eating or exercise.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B9. Given a copy of my treatment plan.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B10. Encouraged to go to a specific group or class to help me cope with my chronic condition.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B11. Asked questions, either directly or on a survey, about my health habits.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Over the past 6 months, when I received care for my chronic conditions, I was:

	None of the time	A Little of the Time	Some of the Time	Most of the Time	Always
B12. Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.	☐1	☐2	☐3	☐4	☐5
B13. Helped to make a treatment plan that I could carry out in my daily life.	☐1	☐2	☐3	☐4	☐5
B14. Helped to plan ahead so I could take care of my condition even in hard times.	☐1	☐2	☐3	☐4	☐5
B15. Asked how my chronic condition affects my life.	☐1	☐2	☐3	☐4	☐5
B16. Contacted after a visit to see how things were going.	☐1	☐2	☐3	☐4	☐5
B17. Encouraged to attend programs in the community that could help me.	☐1	☐2	☐3	☐4	☐5
B18. Referred to a dietitian, health educator, or counselor.	☐1	☐2	☐3	☐4	☐5
B19. Told how my visits with other types of doctors, like an eye doctor or other specialist, helped my treatment.	☐1	☐2	☐3	☐4	☐5
B20. Asked how my visits with other doctors were going.	☐1	☐2	☐3	☐4	☐5

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

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Family Tool

FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Developed by

FAMILY VOICES®

…keeping families at the center
of children's health care

with funding from
Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Services under Cooperative Agreement #U40MC00149-09-00

OCTOBER 2008

INTRODUCTION

Health care visits for children, youth and their families can be more than getting shots, having ears examined or treating the physical symptoms of an illness. Each visit is an opportunity for families, youth and health care providers to partner to assure quality health care for the child and to support the family's needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care. The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following:

- **Families and professionals work together in the best interest of the child and the family.**
- **As the child grows, s/he assumes a partnership role.**
- **There is mutual respect for the skills and expertise each partner brings to the relationship.**
- **Trust is fundamental.**
- **Communication and information sharing are open and objective.**
- **Participants make decisions together.**
- **There is a willingness to negotiate.**

Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

PURPOSE OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Family-centered care is a key aspect of quality in health care for children, youth and their families. This tool is designed to:

1. Increase outpatient health care settings' and families' awareness about the implementation of family-centered care and,
2. Provide an organized way for health care settings to assess current areas of strength and identify areas for growth, plan future efforts and to track progress.

This tool is not designed to provide a score but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. It can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve health care services and supports. The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships.

DESCRIPTION OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

The tool is divided into three major sections:
1) Family/Provider Partnership, 2) Care Setting Practices and Policies and 3) Community Systems of Services and Supports. Within each major section, there are several subtopics that address family-centered care.

Sections and Subtopics of the Family-Centered Care Self-Assessment Tool

Family/Provider Partnership
- The decision-making team
- Supporting the family as the constant in the child's life
- Family-to-family and peer support
- Supporting transition to adulthood
- Sharing successes

Care Setting Practices and Policies
- Giving a diagnosis
- Ongoing care and support
- Addressing child/youth development
- Access to records
- Appointment schedules
- Feedback on care setting practices
- Care setting policies to support family-centered care
- Addressing culture and language in care

Community Systems of Services and Supports
- Information and referral and community-based services
- Community systems integration and care coordination

Each section contains a series of questions that ask about concrete actions that reflect family-centered care. Each section is coded with numbers that indicate which of the ten elements of family-centered care it addresses.

DEFINITIONS OF TERMS

Alternative Healing is the use of herbs, aromatherapy, acupuncture, massage and other remedies that are not considered part of conventional (Western) healthcare treatments.
http://www.aap.org/healthtopics/complementarymedicine.cfm

Care Setting is the physical location where a family and child/youth receives outpatient health services. These services can be provided by a pediatrician, other physician, physician's assistant, nurse, social worker, care coordinator, or any other staff person at this setting.

Children and Youth with Special Health Care Needs have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally.
McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998.

Community-based Services are local, non-medical services that help children and families accomplish daily activities. These services can range from school, childcare, after-school activities, family and peer support and advocacy groups, early intervention or Head Start (a program that helps families learn about and promote the development of their young children).

Consent is approval for healthcare decisions. Individual must have legal authority to provide consent. Generally, the parents or legal guardians of minor children (younger than 18 years old) provide consent. For individuals 18 and older who cannot make their own decisions, a legal guardian or proxy can provide consent.

Cultural Competence requires organizations to have a defined set of values and principles and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally. They should:
- Value diversity,
- Conduct self-assessment,
- Manage the dynamics of difference,
- Acquire and institutionalize cultural knowledge and
- Adapt to diversity and the cultural contexts of the communities they serve.

Organizations should incorporate the above in all aspects of policymaking, administration, practice, service delivery and involve systematically consumers, key stakeholders and communities. Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

(Adapted from Cross et al., 1989) http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html

Family—Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.

Family Supports are services that strengthen and support the family's role as caregiver and decision-maker on behalf of their children.

Family-to-Family and Peer Supports are ways to bring together families, youth and others who share similar life situations so they can share their knowledge, concerns, and experiences with each other.

HIPAA (The Health Insurance Portability and Accountability Act). This is a federal law that protects the privacy of personal health information. You must give permission before personal health information can be shared with:

- Health providers,
- Hospitals,
- Insurance companies, state and federal agencies,
- Schools,
- Employers, or
- Anyone else.

You also have the right to read your medical record and make corrections. For more information visit: http://www.hhs.gov/ocr/hipaa

Linguistic Competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures and dedicated resources to support this capacity.

Goode & Jones (modified 2004). National Center for Cultural Competence, Georgetown University Center for Child & Human Development. http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html.

Provider—in the context of this tool is any person that provides services within the care setting.

Transition to Adulthood—The period of time during which families, youth and providers plan for and develop the process to assure that youth will:

1. Be able to successfully manage all aspects of their healthcare and be prepared to take on adult responsibilities, and ultimately, live as independently as possible and
2. Continue to receive high quality healthcare services.

Directions: Please answer each question by choosing only **one** answer. It may be difficult to rate some items; just answer each question based on your knowledge, experiences and opinions. **There are no right or wrong answers.**

Note: *In each question the term "provider" refers to the health care professionals and other staff within your health care setting.*

THE FAMILY/PROVIDER PARTNERSHIP

The Decision-Making Team

FCC Components: 1, 2, 4, 9

1. Does your provider:

A. Partner with your family to help you define your role in your child's care?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Honor your requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
C. Help you advocate for services and work to improve systems of care, if you so choose?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
D. Act to support your family's chosen role in decision-making?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. Do you and your provider:

A. Work together as partners to make health care decisions?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Talk about the range of treatment and care choices for your child/youth?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
C. Discuss which treatment and care choices would be best for your family and child/youth?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
D. Decide together what the desired outcomes are (e.g., improved health status, better school attendance, less pain, or better involvement with social activities or sports)?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

3. Do choices of diagnostic and treatment approaches take into account:

A. Family and child/youth preferences for site of care, type of provider (gender, language spoken, etc.)?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Child/youth's ability to tolerate the procedure?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
C. How it will affect the family's stress level?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
D. Family insurance status and economic situation?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
E. Family, child/youth work and school schedules?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

4. Does your provider make sure you have the information you need to understand the range of treatment and care choices for your child/youth?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
5. Does your provider make sure all your questions about your child/youth's treatment and care have been answered before you leave the office?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
6. Do you feel comfortable letting your provider know if/when you disagree with medical advice and recommendations for treatment and care of your child/youth?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

The Decision-Making Team Continued

7. Is there a respectful negotiation process to resolve any disagreements you might have about your child/youth's treatment and care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
8. Does your partnership with your provider change over time as your experiences, knowledge and skills change?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Supporting the Family as the Constant in the Child's Life

FCC Components: 1, 2, 4, 10

1. Does your provider ask about:

A. Your family's well-being (adults and other children) and their needs for support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Your support network and the role of faith/religion or other cultural supports?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Your family's concerns and any stresses or successes you may experience as a caregiver?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Depression, domestic violence, substance abuse, housing or lack of food in your family?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

2. Does your provider offer your family:

A. Information about health and wellness appropriate to child/youth's developmental stage? (This includes information about child development, mental health, healthy weight and nutrition, physical activity, sexual development and sexuality, safety/injury prevention, and oral health.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Opportunities to become more knowledgeable about promoting your child's healthy development, such as written information, classes, or connect you with other opportunities in your community?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Family-to-Family and Peer Support

FCC Components: 2, 3, 4, 7, 8, 10

1. Does your provider:

A. Have a process to identify the strengths of families within the practice that they can share with other families?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Actively assist in linking families and youth to other families and youth who share similar life situations, for example, new mothers, children with special health care needs and disabilities, youth in transition, single parent families, grandparents raising grandchildren, etc?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Link families in a way that that reflects the cultural and language preferences of each family?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Help your family/youth make the first connection to support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Offer opportunities for families/caregivers to learn from each other about how the role of families changes as their children/youth get older?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

F. Offer opportunities for children/youth to learn from other youth or those somewhat older how to be active in decision-making about their own care?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

Supporting Transition to Adulthood

FCC Components: 1, 3, 4, 6, 7, 8

1. Does your provider:

A. Discuss your family's, child's (from an early age)/youth's vision for the future? (For example, take time to discuss your family and child's hopes and dreams about education, social relationships, meaningful work, development of independent living skills, and health care.)	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Respect your family's cultural beliefs about when a "child' is fully adult?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
C. Offer opportunities for you and your youth to meet with older youth and young adults who can be successful role models for achieving future goals?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. In preparation for transition, does your provider:

A. Help your youth learn about: managing his/her health, dealing with the logistics of care settings, insurance and decision-making?	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Work with your family to assure that your youth knows about any diagnoses, current treatments and can discuss those with the care provider?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
C. Work with you and your youth to develop a formal healthcare transition plan by age 14 that documents provider, family and youth roles?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
D. Have a formal mechanism to identify adult health care providers for youth in transition?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
E. Have a process to share information with the adult care provider including: transition plans, medical records, key health issues and current family and youth roles in managing care?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
F. Help your youth develop a portable medical record to support interactions with providers?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
G. Work with the adult provider so that both are involved in your youth's care during transition?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply
H. Help your family plan for needed legal solutions and supports if child/youth will be unable to independently manage his/her care?	○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply

Sharing Successes of the Family/Provider Partnership

FCC Components: 10

1. Do families, youth, providers and staff take time to share and enjoy successes?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

CARE SETTING PRACTICES AND POLICIES

Giving a Diagnosis

FCC Components: 1, 2, 6

1. Does your provider:

A. Fully inform your family about all test results, positive and negative?	○ Never	○ Some of the Time	○ Most of the Time	○ Always	
B. Fully inform your family about any diagnosis in a way that you can understand?	○ Never	○ Some of the Time	○ Most of the Time	○ Always	
C. Help your family name and explain your child's diagnosis to others?	○ Never	○ Some of the Time	○ Most of the Time	○ Always	
D. Work together with your family so you can explain how your child's diagnosis might affect how she will be able to participate in school, social, community and faith-based activities?	○ Never	○ Some of the Time	○ Most of the Time	○ Always	○ Does Not Apply

Ongoing Care and Support

FCC Components: 1, 2, 3, 4, 6

1. Does your provider:

A. Help you identify your strengths, skills and knowledge related to your child's health care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Ask you what is working well?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Help you identify areas where you may need additional support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Ask you about your child's care based on your knowledge about your child's temperament, behavior and reactions, and other current personal and family needs and priorities?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Ask your family and child/youth to share information, such as changes in daily routine or new stresses that may provide insight into the interpretation of test results or diagnostic procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Ask your family to initiate consultation appointments or other meetings to discuss changes in your child's care, for example, changes in medications, or other daily procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
G. Fully inform your family about diagnostic and treatment options in a way you can understand?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
H. Encourage questions about treatment options and the need for any procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
I. Offer developmentally appropriate information (for example: stories, workbooks, videos, web-resources, tours) to prepare your child/youth for medical testing and procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
3. Does your provider offer house calls, or other ways that care/treatment can be provided where your child typically spends time?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

4. If your family has difficulty traveling to specialty care settings outside of your community, does your provider work with your child's specialists to help you minimize travel? ○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply

5. If your family uses alternative healing/non-traditional medicine, does your provider work with you to integrate traditional and alternative healing treatments into your child's overall care? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Addressing Child/Youth Development

FCC Components: 3, 4, 6, 8

1. Does your provider:

A. Assess and document the developmental status of your child/youth? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Reassess care approaches at key developmental milestones and transitions? (For example, when your child begins to walk, talk, begins school, enters puberty, and begins middle or high school.) ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Offer your child/youth educational opportunities to support self-care? (For example, know how to make appointments, learn about insurance, medications, diet, and other aspects of health care.) ○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Honor your family's requests about how much you want your child involved in decision-making? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

E. Include your child in making decisions in keeping with age and development? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

F. Explain changes in who can give consent for care as your child gets older? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Access to Records

FCC Component: 9

1. Does your provider:

A. Explain your family's rights and responsibilities under HIPAA (laws about the privacy and sharing or medical information) in a way you can understand? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Have a policy to assure that financial issues, such as copying costs, do not prevent your family from receiving copies of records? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Have a process to assist your family in understanding and interpreting your child's medical record? (For example, provides explanation of medical terms and answers questions about content.) ○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Allow your family or youth to add information into the medical record? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

E. Inform you of all policies that relate to when and how you can see, add to or get copies of your child's records? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. Do all staff that you work with at the care setting give you the same information about policies related to medical records? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Appointment Schedules

FCC Components: 6, 9

1. Does your provider:

A. Recognize your family's schedule and cultural events/holidays as important factors related to scheduling appointments?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Respond to your concerns about proposed scheduling of appointments and procedures?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Honor your request for a longer appointment to discuss complex issues?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Schedule appointments tailored to the needs of your family, and child/youth? (For example, have "no wait" appointments for patients who may have immune system problems or developmental /behavioral issues that make it difficult to sit in the waiting room.)
○ Never ○ Some of the Time ○ Most of the Time ○ Always

Feedback on Care Setting Practices and Policies

FCC Components: 4, 9

1. Are there opportunities for families/youth to provide feedback about care and how the care setting operates? (Examples include surveys, focus groups, and suggestion boxes.)
○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. Does the care setting have a formal advisory committee for family and youth to provide input on policies and practices?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

3. Are families/youth given mentoring, supports and other training to effectively participate on the advisory committee, if they want it?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

4. Does your provider make accommodations for your family and youth to participate in advisory activities? (For example, English or sign language translation, alternate ways to participate, like via conference call or surveys.)
○ Never ○ Some of the Time ○ Most of the Time ○ Always ○ Does Not Apply

Care Setting Policies to Support Family-Centered Care

FCC Components: 4, 9

1. Does your provider share information with families about elements of family-centered care?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. Does your provider explain care setting policies?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

3. Does your provider invite families or youth to do presentations for staff to learn about the family perspective?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

4. Does your provider invite families or youth to do presentations for staff to learn how their cultures and values influence health care decision-making?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

5. Does your provider offer stipends for sharing your time and expertise?
○ Never ○ Some of the Time ○ Most of the Time ○ Always

Addressing Culture and Language in Care

FCC Components: 4

1. Does your provider:

A. Ask your family about any cultural values, beliefs or practices that might relate to your child/youth's care? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Honor your family's beliefs and practices when developing diagnostic and treatment plans? (This includes respect for diet; customs regarding eating, bathing, dressing; religious rituals related to health; modesty concerns such as gender of the provider, expected roles related to gender or generation.) ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Offer trained interpretation (foreign language or sign)? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Let other providers know about your need for interpretation services when making referrals? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

E. Help your family find information and educational materials that you can easily read or that don't need reading, like videos you can watch? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

F. Employ staff that reflect who lives in your community? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

COMMUNITY SYSTEMS OF SERVICES AND SUPPORTS

Information and Referral and Community-based Services

FCC Component: 5

1. Does your provider:

A. Work with your family to identify needed community-based services? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Help your family make the first contact with community-based services? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Follow up to see if your family/child/youth has successfully connected with the service? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Follow up to see if the service was easy to access? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

E. Follow up to see if the service was useful? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

F. Follow up to see if the service was respectful of your family's culture and values? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. As your family circumstances change (changing diagnoses, functional level, child transitions, change in family make up, etc.), does your provider work with your family to review current services and help identify new community-based services you may need? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Community Systems Integration and Care Coordination

FCC Component: 5

1. Does your provider:

A. Include any community-based services your family uses in the medical record? (Examples include early intervention, Head Start, childcare, community recreation programs, vocational rehab, faith-based activities.)	○ Never ○ Some of the Time ○ Most of the Time ○ Always
B. Have a staff person that helps your family connect with needed services?	○ Never ○ Some of the Time ○ Most of the Time ○ Always

Thank you for taking the time to complete this self-assessment tool. We welcome your feedback. Visit www.familyvoices.org to share your ideas and suggestions for how we might improve future versions.

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

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Provider Tool

FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Developed by

FAMILY VOICES®

…keeping families at the center
of children's health care

with funding from
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INTRODUCTION

Health care visits for children, youth and their families can be more than getting shots, having ears examined or treating the physical symptoms of an illness. Each visit is an opportunity for families, youth and health care providers to partner to assure quality health care for the child and to support the family's needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care. The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following:

- **Families and professionals work together in the best interest of the child and the family.**
- **As the child grows, s/he assumes a partnership role.**
- **There is mutual respect for the skills and expertise each partner brings to the relationship.**
- **Trust is fundamental.**
- **Communication and information sharing are open and objective.**
- **Participants make decisions together.**
- **There is a willingness to negotiate.**

Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

PURPOSE OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Family-centered care is a key aspect of quality in health care for children, youth and their families. This tool is designed to:

1. Increase outpatient health care settings' and families' awareness about the implementation of family-centered care and,
2. Provide an organized way for health care settings to assess current areas of strength and identify areas for growth, plan future efforts and to track progress.

This tool is not designed to provide a score but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. It can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve health care services and supports. The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships.

DESCRIPTION OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

The tool is divided into three major sections:
1) Family/Provider Partnership, 2) Care Setting Practices and Policies and 3) Community Systems of Services and Supports. Within each major section, there are several subtopics that address family-centered care.

Sections and Subtopics of the Family-Centered Care Self-Assessment Tool

Family/Provider Partnership

- The decision-making team
- Supporting the family as the constant in the child's life
- Family-to-family and peer support
- Supporting transition to adulthood
- Sharing successes

Care Setting Practices and Policies

- Giving a diagnosis
- Ongoing care and support
- Addressing child/youth development
- Access to records
- Appointment schedules
- Feedback on care setting practices
- Care setting policies to support family-centered care
- Addressing culture and language in care

Community Systems of Services and Supports

- Information and referral and community-based services
- Community systems integration and care coordination

Each section contains a series of questions that ask about concrete actions that reflect family-centered care. Each section is coded with numbers that indicate which of the ten elements of family-centered care it addresses.

DEFINITIONS OF TERMS

Alternative Healing is the use of herbs, aromatherapy, acupuncture, massage and other remedies that are not considered part of conventional (Western) healthcare treatments.
http://www.aap.org/healthtopics/complementarymedicine.cfm

Care Setting is the physical location where a family and child/youth receives outpatient health services. These services can be provided by a pediatrician, other physician, physician's assistant, nurse, social worker, care coordinator, or any other staff person at this setting.

Children and Youth with Special Health Care Needs have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally.
McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998.

Community-based Services are local, non-medical services that help children and families accomplish daily activities. These services can range from school, childcare, after-school activities, family and peer support and advocacy groups, early intervention or Head Start (a program that helps families learn about and promote the development of their young children).

Consent is approval for healthcare decisions. Individual must have legal authority to provide consent. Generally, the parents or legal guardians of minor children (younger than 18 years old) provide consent. For individuals 18 and older who cannot make their own decisions, a legal guardian or proxy can provide consent.

Cultural Competence requires organizations to have a defined set of values and principles and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally. They should:

- Value diversity,
- Conduct self-assessment,
- Manage the dynamics of difference,
- Acquire and institutionalize cultural knowledge and
- Adapt to diversity and the cultural contexts of the communities they serve.

Organizations should incorporate the above in all aspects of policymaking, administration, practice, service delivery and involve systematically consumers, key stakeholders and communities. Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

(Adapted from Cross et al., 1989) http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html

Family—Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.

Family Supports are services that strengthen and support the family's role as caregiver and decision-maker on behalf of their children.

Family-to-Family and Peer Supports are ways to bring together families, youth and others who share similar life situations so they can share their knowledge, concerns, and experiences with each other.

HIPAA (The Health Insurance Portability and Accountability Act). This is a federal law that protects the privacy of personal health information. You must give permission before personal health information can be shared with:

- Health providers,
- Hospitals,
- Insurance companies, state and federal agencies,
- Schools,
- Employers, or
- Anyone else.

You also have the right to read your medical record and make corrections. For more information visit: http://www.hhs.gov/ocr/hipaa

Linguistic Competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures and dedicated resources to support this capacity.

Goode & Jones (modified 2004). National Center for Cultural Competence, Georgetown University Center for Child & Human Development. http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html.

Provider—in the context of this tool is any person that provides services within the care setting.

Transition to Adulthood—The period of time during which families, youth and providers plan for and develop the process to assure that youth will:

1. Be able to successfully manage all aspects of their healthcare and be prepared to take on adult responsibilities, and ultimately, live as independently as possible and
2. Continue to receive high quality healthcare services.

Directions: Please answer each question by choosing only **one** answer. It may be difficult to rate some items; just answer each question based on your knowledge, experiences and opinions. **There are no right or wrong answers.**

Note: *In each question the term "provider" refers to the health care professionals and other staff within your health care setting.*

THE FAMILY/PROVIDER PARTNERSHIP

The Decision-Making Team

FCC Components: 1, 2, 4, 9

1. Do you and your staff:

A. Partner with families to help define their role in their child's care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Honor families' requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Help families advocate for services and work to improve systems of care, if they so choose?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Act to support each family's chosen role?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

2. Do you and your staff:

A. Work in partnership with families/youth to make health care decisions?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Talk about the range of treatment and care choices for the child/youth?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Discuss which treatment and care choices would be best for the family and child/youth?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Make sure the family and child/youth understand the range of treatment and care choices?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. When deciding on treatment options, do you and your staff work with the family and child/youth to decide what the desired outcomes are (e.g., improved health status, better school attendance, less pain, or better involvement with social or sports activities)?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

3. Do choices of diagnostic and treatment approaches take into account:

A. Family/child youth preferences for site of care, type of provider (gender, language spoken, etc.)?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Child/youth's ability to tolerate the procedure?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Any follow up medical treatment the child/youth will need?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Family insurance status and economic situation?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Family and child/youth work and school schedules?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

4. Do you and your staff make sure all the family's and child/youth's questions have been answered before they leave the office?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

The Decision-Making Team Continued

5. Do you and your staff make sure the family and child/youth feel comfortable enough to let you know if they disagree with medical advice and recommendations for treatment and care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
6. Is there a respectful negotiation process to resolve any disagreements about a child/youth's treatment and care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
7. Does your partnership with families change over time as their experiences, knowledge and skills change?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Supporting the Family as the Constant in the Child's Life

FCC Components: 1, 2, 4, 6

1. Do you and your staff ask about:

A. The family's well-being (adults and other children) and their needs for support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. The family's support network and the role of faith/religion or other cultural supports?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. The family's concerns and any stresses or successes they may experience as a caregiver?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Depression, domestic violence, substance abuse, housing or food insecurity?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

2. Do you and your staff offer families:

A. Information about health and wellness appropriate to child/youth's developmental stage? (This includes information about child development, mental health, healthy weight and nutrition, physical activity, sexual development and sexuality, safety/injury prevention, and oral health.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Opportunities to become more knowledgeable about promoting their child's healthy development, such as written information, classes, or connect them with other opportunities in the community?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Family-to-Family and Peer Support

FCC Components: 2, 4, 7, 8

1. Do you and your staff:

A. Have a process to identify the strengths of families within the practice that they can share with other families?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Actively assist in linking families to other families who share similar life situations, for example, new mothers, children with special health care needs and disabilities, single parent families, grandparents raising grandchildren, etc?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Link families in a way that that reflects the cultural and language preferences of each family?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Help families/youth make the first connection to support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

E. Offer peer mentoring/support opportunities for families/caregivers to be supported in their changing roles from decision-makers to supporting their children/youth in making decisions? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

F. Offer peer mentoring/support opportunities to help children/youth learn how to be active in decision-making about their own care? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Supporting Transition to Adulthood

FCC Components: 1, 3, 4, 6, 7, 8

1. Do you and your staff:

A. Ask families and children (from an early age)/youth about their vision for the future? (For example, take time to discuss the family's and child's hopes and dreams about education, social relationships, development of independent living skills, meaningful work, and health care.) ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Connect families and youth with information and resources to support achieving their vision in ways that respect their cultural beliefs about roles and expectations in adulthood? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Offer opportunities for families and youth to meet with older youth and young adults as role models for achieving future goals? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

2. In preparation for transition, do you and your staff:

A. Help youth learn about: managing their health, dealing with the logistics of care settings, insurance and decision-making? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

B. Work with the family to assure that the youth knows about any diagnoses, current treatments and can discuss those with the care provider? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

C. Work with the family and youth to develop a formal healthcare transition plan by age 14 that documents provider, family and youth roles? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

D. Have a formal mechanism to identify adult health care providers for youth in transition? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

E. Have a process to share information with adult care providers including: current care plans, transition plans, medical records, key health issues and current family and youth roles in managing care? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

F. Help youth develop a portable medical record to support their interactions with new providers? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

G. Work with adult providers so they are involved in a youth's care during transition? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

H. Help families plan for needed legal solutions and supports if their child/youth will be unable to independently manage his/her care? ○ Never ○ Some of the Time ○ Most of the Time ○ Always

Sharing Successes of the Family/Provider Partnership

FCC Component: 10

1. Do you and your staff take time to document and share successes with families?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
2. Do you and your staff take time to document and share successes with each other?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

CARE SETTING PRACTICES AND POLICIES

Giving a Diagnosis

FCC Components: 1, 2, 6

1. Do you and your staff:

A. Fully inform families about all test results, positive and negative?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Fully inform families about any diagnosis in a way they can understand?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Help families name and explain their child's diagnosis to others?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Work together with families so they can explain how their child's diagnosis might affect how s/he will be able to participate in school, community and faith-based activities?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Ongoing Care and Support

FCC Components: 1, 2, 3, 4, 6

1. Do you and your staff:

A. Help families identify their strengths, skills and knowledge related to their child's health care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Ask families what is working well?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Help families identify areas where they may need additional support?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Ask families to provide input about their child's care based on their knowledge about their child's temperament, behavior and reactions, and other current personal and family needs and priorities?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Ask families, children and youth to share information, such as a change in daily routine or new stress that may provide insight into the interpretation of test results or diagnostic procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Encourage families to initiate consultation appointments or other meetings to discuss changes in their child's care, for example, changes in medications, or other daily procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
G. Fully inform families about diagnostic and treatment options in a way they can understand?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
H. Encourage questions about treatment options and the need for any procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
I. Offer developmentally appropriate information (for example: stories, workbooks, videos, web-resources, tours) to prepare the family/child/youth for medical testing and procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

2. Do you and your staff offer house calls, home care, or other ways that care/treatment can be provided in natural settings?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
3. If a family has difficulty traveling to specialty care settings outside of your community, can you and your staff receive partner with specialists to enhance the amount of care you can provide within your care setting?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
4. If a family uses alternative and traditional medicine, do you and your staff work with the family to integrate traditional and alternative healing treatments into the child/youth's overall care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Addressing Child/Youth Development

FCC Components: 3, 4, 6, 8

1. Do you and your staff:

A. Assess and document the developmental status of each child/youth?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Reassess care approaches at key developmental milestones and transitions? (For example, when the child begins to walk, talk, begins school, enters puberty, and begins middle or high school.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Offer children/youth educational opportunities to support self-care? (For example, know how to make appointments, learn about insurance, medications, diet, and other aspects of health care.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Honor the family's request about how much they want their child involved in decision-making?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Include child in making decisions in keeping with age and development?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Explain changes in who can give consent for care as the family's child gets older?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Access to Records FCC Component: 9

1. Do you and your staff:

A. Explain family's rights and responsibilities under HIPAA in a way they can understand?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Have a policy to assure that financial issues, such as copying costs, do not prevent families from receiving copies of records?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Have a process to assist families in understanding and interpreting their child's medical record? (For example, provide explanations of medical terms and answer questions about content.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Let families or youth add information to their medical records?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Assure that all staff are aware of policies and procedures related to access to medical records?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Appointment Schedules FCC Components: 6, 9

1. Do you and your staff:

A. Recognize families' schedules and cultural events as important factors related to scheduling appointments?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Respond to families' concerns about proposed scheduling of appointments and procedures?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Honor families' requests for longer appointments to discuss complex issues?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Schedule appointments tailored to the needs of the child/youth and family? (For example, have "no wait" appointments for patients who may have immune system problems or developmental/behavioral issues that make it difficult to sit in the waiting room.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Feedback on Care Setting Practices FCC Components: 4, 9

1. Are there opportunities for families/youth to provide feedback about care? (Examples include surveys, focus groups, suggestion boxes.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
2. Does your practice have a formal advisory committee for families and youth to provide input on policies and practices?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
3. Are families/youth offered mentoring, or other supports and training to effectively participate on the advisory committee?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
4. Do you and your staff make accommodations for families and youth who need supports to participate in advisory activities? (For example, English or sign language translation, alternate ways to participate, like via conference call or surveys.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Care Setting Policies to Support Family-Centered Care

FCC Components: 4, 9

1. Do you and your staff:

A. Make sure families are knowledgeable about care setting policies and practices?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Have a policy about delivering family-centered care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Share information with families about elements of family-centered and culturally and linguistically competent care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Create job descriptions that include roles and responsibilities for all providers and staff related to family-centered and culturally and linguistically competent care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Provide orientation, training and support to staff and others related to family-centered and culturally and linguistically competent care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Evaluate staff performance and effectiveness in providing family-centered care and culturally and linguistically competent care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
G. Invite families or youth to give presentations for staff to learn about the family perspective?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
H. Invite families or youth to do presentations for staff to learn how their cultures and values influence decision-making around their health care needs?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
I. Provide stipends to family and youth who share their knowledge and expertise with your staff?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Addressing Culture and Language in Care

FCC Components: 4

1. Do you and your staff:

A. Ask families about any cultural values, beliefs or practices that might relate to their child/youth's care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Honor families beliefs and practices when developing diagnostic and treatment plans? (This includes respect for diet; customs regarding eating, bathing, dressing; religious rituals related to health; modesty concerns such as gender of the provider, expected roles related to gender or generation.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Offer trained interpretation (foreign language or sign)?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Document the need for interpretation services when making referrals?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Help families find information and educational materials they can easily read or that don't need reading, like videos to watch?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Employ staff that reflect the diversity of your community?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

3. Do you have policies to institutionalize these care setting practices? ○ Yes ○ No

4. Are all staff informed about Care Setting Policies and Practices? ○ Yes ○ No

5. Are all families informed about Care Setting Policies and Practices? ○ Yes ○ No

COMMUNITY SYSTEMS OF SERVICES AND SUPPORTS

Information and Referral and Community-Based Services

FCC Component: 5

1. Do you and your staff:

A. Work with families to identify needed community-based services?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Help families make the first contact with community-based services?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
C. Follow up to see if the family and child/youth has successfully connected with the service?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
D. Follow up to see if the service was easy to access by the family?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
E. Follow up to see if the service was useful to the family?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
F. Follow up to see if the service was respectful of the family's culture and values?	○ Never	○ Some of the Time	○ Most of the Time	○ Always
2. As family circumstances change (changing diagnoses, functional level, child transitions, change in family make up, etc.), do you and your staff work with the family to review current services and help identify new community-based services they may need?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Community Systems Integration and Care Coordination

FCC Component: 5

1. Do you and your staff:

A. Document the community-based services families use? (Examples include early intervention, Head Start, childcare, community recreation programs, vocational rehab, faith-based activities.)	○ Never	○ Some of the Time	○ Most of the Time	○ Always
B. Have a staff person or care coordinator that helps families coordinate care?	○ Never	○ Some of the Time	○ Most of the Time	○ Always

Thank you for taking the time to complete this self-assessment tool. We welcome your feedback. Visit www.familyvoices.org to share your ideas and suggestions for how we might improve future versions.

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

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

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

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.
____
____

Denise Rousseau, Ph.D.
____
____

Stephen M. Shortell, Ph.D.
____
____

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.

Statement	1	2	3	4	5
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.

Statement	Strongly Disagree 1	Disagree 2	Neither Disagree Nor Agree 3	Agree 4	Strongly Agree 5
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 <u>between ICU physicians</u>. 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 <u>Medical Director</u> 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 <u>Nurse Manager/Head Nurse</u> 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 <u>Nurse Manager/Head Nurse</u> 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 <u>one</u> 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.

THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

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

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.

Denise Rousseau, Ph.D.

6Wephen M. Shortell, Ph.D.

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)
<u>General Relationships and Communications</u>: 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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[*] Excerpted from The Reliability/Safety Survey. Copyright 1987, Human Synergistics/Center for Applied Research. Used with permission.

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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[*] Excerpted from Level V: Organizational Culture Inventory. Copyright 1987, Human Synergistics/Center for Applied Research. Used with permission.

SECTION FOUR: TEAMWORK AND LEADERSHIP

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

(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.

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

<u>General:</u> 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 <u>between ICU nurses and physicians</u>. Based on your experience in this unit, how likely is it that:

(2:107)

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.	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**
						(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**	**Effective 4**	**Very Effective 5**	**Not Applicable (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	Effective 4	Very Effective 5	Not Applicable (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**	**Agree 4**	**Strongly Agree 5**
					(3:30)
B. The ICU <u>Medical Director</u> 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 <u>Nurse Manager/Head Nurse</u> 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 <u>Nurse Manager/Head Nurse</u> 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 <u>all</u> that apply)

1. ____LPN (3:76-81)
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?

1. ___US native (3:99)
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?

____ (l) 30 minutes or less (3:116)

____ (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.

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

Contact Information:

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

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THE ORGANIZATION AND MANAGEMENT OF INTENSIVE CARE UNITS

School of Public Health
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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)

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.

Denise Rousseau, Ph.D.

Stephen M. Shortell, Ph.D.

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 Fommunications 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		3		

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		4	

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, <u>circle</u> 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 <u>other ICUs within your area</u>, how does your unit compare on the following items?

(2:83)

	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 PHYSICIANS

IV--PART A: Consider what happens when there is a disagreement or conflict <u>between ICU physicians</u>. 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 <u>between ICU nurses and physicians</u>. 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 ZLOOEHLJQRUHGRUDYRLGHG					

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		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		5

SECTION SIX: SATISFACTION

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

Very Dissat-isfied	Dissat-isfied	Neither Dissatisfied Nor Satisfied	Satisfied	Very Satisfied
1	2	3	4	5

7KDQN \RX YHU\ PXFK IRU \RXU KHOS DQG FRRSHUDWLRQ LQ DQVZHULQJ WKLV TXHVWLRQQDLUH
3OHDVH UHWXUQ LQ WKH DGGUHVVHG SRVWDJH SDLG HQYHORSH SURYLGHG

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)

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.

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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.

Denise Rousseau, Ph.D.

Stephen M. Shortell, Ph.D.

SECTION ONE: RELATIONSHIPS AND COMMUNICATIONS WITHIN THE ICU

I. For each of the following statements, please <u>circle</u> 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
<u>Nurse-to-Nurse Relationships</u>: 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
<u>Nurse-to-Physician Relationships</u>: 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

<u>Physician Leadership:</u> 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 <u>all</u> 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

<u>General:</u> 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, <u>circle</u> 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 <u>other ICUs within your area</u>, 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 <u>between ICU nurses</u>. 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 <u>between ICU nurses and physicians</u>. 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, <u>circle</u> 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 <u>Medical Director</u> 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 <u>Nurse Manager/Head Nurse</u> 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? <u>Circle</u> the appropriate response.

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

- Requests and questions related to the Primary Care Assessment Survey (PCAS) can be made by following the link: http://160.109.101.132/icrhps/resprog/thi/pcas.asp.

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Primary Care Assessment Survey

The Health Institute
New England Medical Center

NOTE: This survey document contains the 51 items that comprise the PCAS, along with supplementary items used for analysis and interpretation. The 51 PCAS items are denoted with a box drawn around the item number.

INSTRUCTIONS

For each question, fill in one box & or write in your answer ____ on the line provided.

There are no wrong answers.

Please answer every question (unless you are asked to skip questions because they don't apply). It is o.k. to take breaks -- you do not have to complete the whole survey in one sitting.

If you find a question too private or personal, you can skip it and answer the other questions. In any case, your answers are completely confidential and will never be shared with any one.

If you have questions, please call ____ (*Project should provide a name and toll-free number.)*

When you are finished, please return the survey in the postage paid envelope provided.

Thank you for participating.

YOUR REGULAR DOCTOR

1. Is there one particular doctor that you consider to be your **regular personal doctor?**

[1]	[2]
Yes	No

⟶ GO TO QUESTION 34 ON PAGE 13

↓

---

2. How **long** has this person been your doctor?

Less than 6 months	Between 6 months and 1 year	1 to 2 years	3 to 5 years	More than 5 years
[1]	[2]	[3]	[4]	[5]

---

3. Is this the person you call when you have a **medical problem** or **question**?

Yes	No
[1]	[2]

---

4. Does this doctor handle **most** of your health care needs?

Yes	No
[1]	[2]

---

5. When was your **last** medical visit with your **regular personal doctor?**

Less than 1 month ago	1 to 3 months ago	4 to 6 months ago	7 months to 1 year ago	More than 1 year ago
[1]	[2]	[3]	[4]	[5]

---

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

Definitely yes	Probably yes	Not sure	Probably not	Definitely not
[1]	[2]	[3]	[4]	[5]

The questions from here through page 13 are about care you have received from the doctor you think of as your regular doctor.

7a. How many **minutes** does it usually take you to get to your regular doctor's office? ➔

[1] Less than 15
[2] 16 to 30
[3] 31 to 60
[4] More than 60

b. How would you rate the convenience of your regular doctor's office **location**? ➔

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

8a. What **additional** hours would you like your doctor's office to be open? (fill in all that apply) ➔

[1] Early morning
[2] Evenings
[3] Weekends
[4] None, I am satisfied with the hours

b. How would you rate the **hours** that your doctor's office is open for medical appointments? ➔

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

9a. When you are **sick** and call the doctor's office for an appointment, how quickly do they usually **see** you? ➔

[1] The same day
[2] The next day
]3} In 2 to 3 days
[4] In 4 to 5 days
]5] In more than 5 days

b. How would you rate the usual **wait** for an appointment when you are sick and call the doctor's office asking **to be seen**? ➔

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

10a. How many minutes **late** do your appointments at your doctor's office usually begin? ➔

[1] None, they begin on time
[2] Less than 5 minutes late
[3] 6 to 10 minutes late
[4] 11 to 20 minutes late
[5] 21 to 30 minutes late
[6] 31 to 45 minutes late
[7] More than 45 minutes late

b. ➔ How would you rate the amount of time you **wait** at your doctor's office for your appointment to **start**?

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

11a. Do you ever put off **going to the doctor** because it is too expensive? ➔

Yes, often	Yes, occasionally	No, never
[1]	[2]	[3]

b. ➔ How would you rate the amount of money you pay for **doctor visits**

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

12a. Do you ever **skip medication or treatments** because they are too expensive? ➔

Yes, often	Yes, occasionally	No, never
[1]	[2]	[3]

b. ➔ How would you rate the amount of money you pay for **medication & other prescribed treatments**

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

13. Thinking about the times you have needed to **see or talk to** your doctor, how would you rate the following:

a. Ability to **get through to** the doctor's office by phone?

Very poor	Poor	Fair	ood	Very good	Excellent
[1]	[2]	[3]	[4]	[5]	[6]

b. Ability to **speak to** your doctor by phone when you have a question or need medical advise?

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

14a. When you go for a **check-up or routine care**, how often do you see your **regular doctor** (not an assistant or partner)? ➔

Always	Almost Always	A lot of the time	Some of the time	Almost never	Never
[1]	[2]	[3]	[4]	[5]	[6]

b. How would you rate this?

➔

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

15a. When you are **sick** and go to the doctor, how often do you see your **regular doctor** (not an assistant or partner)? ➔

Always	Almost Always	A lot of the time	Some of the time	Almost never	Never
[1]	[2]	[3]	[4]	[5]	[6]

b. How would you rate this?

➔

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

16. Thinking about the **technical aspects** of your care, how would you rate the following:

a. Thoroughness of doctor's **physical examination** of you to check a health problem you have?

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

b. How often do you question whether your doctor's **diagnosis** of your health problem is right?

Always	Almost always	A lot of the time	Some of the time	Almost never	Never
[1]	[2]	[3]	[4]	[5]	[6]

17. Thinking about **talking** with your regular doctor, how would you rate the following:

	[1] Very poor	[2] Poor	[3] Fair	[4] Good	[5] Very good	[6] Excellent
a. Thoroughness of your doctor's **questions** about your symptoms and how you are feeling	π	π	π	π	π	π
b. **Attention** your doctor gives to what you have to say	π	π	π	π	π	π
c. Doctor's **explanations** of your health problems or treatments that you need	π	π	π	π	π	π
d. Doctor's **instructions** about symptoms to report and when to seek further care	π	π	π	π	π	π
e. Doctor's advice and help in **making decisions** about your care	π	π	π	π	π	π

18. How often do you leave your doctor’s office with **unanswered questions**?

				π	
Always	Almost always	A lot of the time	Some of the time	Almost never	Never
[1]	[2]	[3]	[4]	[5]	[6]

---

19. Thinking about the **personal aspects** of the care you receive from your regular doctor, how would you rate the following:

	[1] Very poor	[2] Poor	[3] Fair	[4] Good	[5] Very good	[6] Excellent
a. Amount of **time** your doctor spends with you	π	π	π	π	π	π
b. Doctor’s **patience** with your questions or worries	π	π	π	π	π	π
c. Doctor’s **friendliness and warmth** toward you	π	π	π	π	π	π
d. Doctor’s **caring and concern** for you	π	π	π	π	π	π
e. Doctor’s **respect** for you	π	π	π	π	π	π

---

20. Think about **advice** your regular doctor gives you on ways to avoid illness and stay healthy. Would you say the doctor gives:

(answer each line)	[1] Yes	[2] No
a. Too **little** advice	π	π
b. Too **much** advice	π	π

21. Which of the following has your regular doctor **ever** talked to you about?

(answer each line)	[1] Yes, in the last 3 years	[2] Yes, more than 3 years ago	[3] Yes, I don't remember when	[4] No
a. Smoking	π	π	π	π
b. Alcohol Use	π	π	π	π
c. Seat belt use	π	π	π	π
d. Diet	π	π	π	π
e. Exercise	π	π	π	π
f. Stress	π	π	π	π
g. Safe sex	π	π	π	π

---

22. Which of the following have you **ever** done **because of your doctor's advice**?

(answer each line)	[1] Yes	[2] No
a. Tried to cut down or quit smoking	π	π
b. Tried to drink less alcohol	π	π
c. Wore your seat belt more	π	π
d. Changed your diet in any way	π	π
e. Done more exercise	π	π
f. Tried to relax or reduce your stress	π	π
g. Practiced safer sex	π	π

23. Thinking about how much you **TRUST** your doctor, how strongly do you **agree** or **disagree** with the following statements:

	[1] Strongly agree	[2] Agree	[3] Not sure	[4] Disagree	[5] Strongly disagree
a. I can tell my doctor **anything**, even things that I might not tell anyone else	π	π	π	π	π
b. My doctor sometimes **pretends** to know things when he/she is really not sure	π	π	π	π	π
c. I completely trust my doctor’s **judgments** about my medical care	π	π	π	π	π
d. My doctor cares more about **holding down costs** than about doing what is needed for my health	π	π	π	π	π
e. My doctor would always tell me the **truth** about my health, even if there was bad news	π	π	π	π	π
f. My doctor cares **as much** as I do about my health	π	π	π	π	π
g. If a mistake was made in my treatment, my doctor would try to **hide** it from me	π	π	π	π	π

---

24. All things considered, how much do you trust your doctor?

0 1 2 3 4 5 6 7 8 9 a

Not at all Completely

25. Thinking about how well your doctor **knows you**, how would you rate the following?

	[1] Very poor	[2] Poor	[3] Fair	[4] Good	[5] Very good	[6] Excellent
a. Doctor’s knowledge of your **entire medical history**	π	π	π	π	π	π
b. Doctor’s knowledge of your **responsibilities at work or home**	π	π	π	π	π	π
c. Doctor’s knowledge of what **worries** you most about your health	π	π	π	π	π	π
d. Doctor’s knowledge of **you as a person** (your values and beliefs)	π	π	π	π	π	π

---

26. If I were unconscious or in a coma, my doctor would know what I would want done for me.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
[1]	[2]	[3]	[4]	[5]

27. Are there **other** doctors or nurses who <u>work in your doctor's office</u>, who play an **important role** in your care?

[1] Yes	[2] No

→ GO TO QUESTION 30 ON PAGE 11

---

28. Thinking about these **other** doctors or nurses who play an important role in your care, how would you rate:

	[1] Very poor	[2] Poor	[3] Fair	[4] Good	[5] Very good	[6] Excellent
a. Their knowledge of **you as a person** (your values and beliefs)	π	π	π	π	π	π
b. Their knowledge about your health	π	π	π	π	π	π
c. The **quality** of care they provide	π	π	π	π	π	π
d. The **coordination** between them and your regular doctor	π	π	π	π	π	π
e. Their **explanations** of your health problems or treatments that you need	π	π	π	π	π	π

π Not applicable, only my regular doctor does this

---

29. How much would you say your **regular doctor** knows about the care you receive from these **other** doctors or nurses (for example: visits that you make, treatments recommended)?

Knows absolutely everything	Knows almost everything	Knows some things	Knows very little	Knows nothing at all
[1]	[2]	[3]	[4]	[5]

30. Has your doctor ever recommended that you see a **different doctor** for a specific health problem?

[1] Yes
[2] No → GO TO QUESTION 32 ON NEXT PAGE

↓

---

31. Thinking about the times your doctor has recommended you see a **different doctor** for a specific health problem, how would you rate the following:

	[1] Very poor	[2] Poor	[3] Fair	[4] Good	[5] Very good	[6] Excellent
a. Help your regular doctor gave you in deciding **who to see** for specialty care	π	π	π	π	π	π
b. Help your regular doctor gave you in **getting an appointment** for specialty care you needed	π	π	π	π	π	π
c. Regular doctor's involvement in your care when you were being treated by a **specialist or were hospitalized**	π	π	π	π	π	π
d. Regular doctor's **communication with specialists** or other doctors who saw you	π	π	π	π	π	π
e. Help your regular doctor gave you in understanding what the **specialist or other doctor** said about you	π	π	π	π	π	π
f. Quality of **specialists or other doctors** your regular doctor sent you to	π	π	π	π	π	π

32. All things considered, how **satisfied** are you with your **regular doctor**?

[1] Completely satisfied, couldn’t be better
[2] Very satisfied
[3] Somewhat satisfied
[4] Neither satisfied nor dissatisfied
[5] Somewhat dissatisfied
[6] Very dissatisfied
[7] Completely dissatisfied, couldn’t be worse

---

33. The information you have provided is **completely private**. Your individual answers will **never** be shown to your doctor, health plan, or anyone else.

For purposes of this research, however, it is helpful for us to know your doctor’s name. It lets us determine whether your present doctor is different from the one caring for you when you first participated in this study (1996).

What is your **regular doctor’s** name? ______________________ (please print)

BACKGROUND INFORMATION

34. How old are you? ______ **years** old

35. Are you male or female?

π	π
Male	Female
[1]	[2]

36. Which of the following best describes your **racial or ethnic background** (fill in <u>one</u> box)?

π	π	π	π	π
Hispanic or Latino	White or Caucasian	Black or African-American	Asian	Other
[1]	[2]	[3]	[4]	[5]

37. How many people **live in** your household, including yourself, other adults, and any children?

_______ **people**

38. Approximately what was **the total income** of your household last year before taxes (fill in <u>one</u> box)?

π	π	π	π	π
Less than $20,000	$20,000 to $39,999	$40,000 to $59,999	$60,000 to $79,999	$80,000 or more
[1]	[2]	[3]	[4]	[5]

39. What is your **current** marital status (fill in <u>one</u> box)?

π	π	π	π	π
Married	Separated	Divorced	Widowed	Never been married
[1]	[2]	[3]	[4]	[5]

40. What is the **highest grade** you completed in school?

1 2 3 4 5 6 7 8	9 a b c	d e f g	h+
Grade School	High School	College	Post Grad

---

41. How would you describe your **cigarette** smoking habits?

[1]	[2]	[3]
Never smoked	Used to smoke	Now smoke
π	π	π →
↓	↓	

b. How many cigarettes a day do you smoke?

_______ cigarettes per day

---

42. How often do you **buckle your safety belt** when driving or riding in an automobile?

π	π	π	π	π
None of the time	A little of the time	Some of the time	Most of the time	All of the time
[1]	[2]	[3]	[4]	[5]

---

43. How many drinks of the following **alcoholic beverages** do you have during a typical week (including weekends)?

(answer each line)

a. __________ bottles or cans of beer

b. __________ glasses of wine or wine coolers

c. __________ mixed drinks or shots of liquor

---

44. How many times per week do you **exercise** for 20 minutes or more (for example, take a brisk walk)?

__________ times per week

45. Thinking about the **amount of stress** in your life, would you say that most days are:

π	π	π	π	π
Extremely stressful	Quite stressful	A bit stressful	Not very stressful	Not at all stressful
[1]	[2]	[3]	[4]	[5]

46. How **tall** are you? _______ feet ______ inches

47. How much do you **weigh**? ______ pounds

YOUR HEALTH

48. In general, would you say your health is:

π	π	π	π	π
Excellent	Very good	Good	Fair	Poor
[1]	[2]	[3]	[4]	[5]

---

49. The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	[1] Yes, limited a lot	[2] Yes, limited a little	[3] No, not limited at all
a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	π	π	π
b. Climbing **several** flights of stairs	π	π	π

---

50. During the **past 4 weeks**, have you had any of the following problems with your work or regular daily activities **as a result of your physical health**?

	[1] Yes	[2] No
a. **Accomplished less** than you would like	π	π
b. Were limited in the **kind** of work or other activities	π	π

---

51. During the **past 4 weeks**, have you had any of the following problems with your work or regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	[1] Yes	[2] No
a. **Accomplished less** than you would like	π	π
b. Didn’t do work or other activities as **carefully** as usual	π	π

52. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

π	π	π	π	π
Not at all	A little bit	Moderately	Quite a bit	Extremely
[1]	[2]	[3]	[4]	[5]

53. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	[1] All of the time	[2] Most of the time	[3] A good bit of the time	[4] Some of the time	[5] A little of the time	[6] None of the time
a. Have you felt calm and peaceful?	π	π	π	π	π	π
b. Did you have a lot of energy?	π	π	π	π	π	π
c. Have you felt downhearted and blue?	π	π	π	π	π	π

54. During the **past 4 weeks**, how much of the time have your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

π	π	π	π	π
All of the time	Most of the time	Some of the time	A little of the time	None of the time
[1]	[2]	[3]	[4]	[5]

55. Please think back to this same time **4 years ago** and answer each question below as best you can.

a. Compared to **4 years ago**, are you more or less limited **now** in your everyday physical activities because of your health?

☐	☐	☐	☐	☐
A lot more limited now	Somewhat more limited now	About the same	Somewhat less limited now	A lot less limited now
[1]	[2]	[3]	[4]	[5]

b. Compared to **4 years ago**, how often do you feel bothered by emotional problems, such as feeling anxious, depressed, or irritable **now**?

☐	☐	☐	☐	☐
I feel this way a lot more often now	I feel this way a little more often now	About the same	I feel this way a little less often now	I feel this way a lot less often now
[1]	[2]	[3]	[4]	[5]

c. Compared to **4 years ago**, how would you rate your health in general **now**?

☐	☐	☐	☐	☐
Much better now than four years ago	Somewhat better now than four years ago	About the same	Somewhat worse now than four years ago	Much worse now than four years ago
[1]	[2]	[3]	[4]	[5]

---

56. **Has a doctor ever told you that you had**:	[1] Yes	[2] No
a. Hypertension or high blood pressure	☐	☐
b. A heart attack in the **last year** (myocardial infarction)	☐	☐
c. Congestive heart failure (heart failure or enlarged heart)	☐	☐
d. Diabetes (high blood sugar)	☐	☐
e. Angina (An-JI-na or AN-jin-na)	☐	☐
f. Cancer (except skin)	☐	☐
g. Migraine headaches	☐	☐

	[1] Yes	[2] No
57. **Do you now have any of the following conditions?**:		
a. Seasonal allergies (such as hay fever)	π	π
b. Other allergies (such as dust, pets or food)	π	π
c. Arthritis or any kind of rheumatism	π	π
d. Chronic back pain or sciatica	π	π
e. Blindness or trouble seeing with one or both eyes, **even** when wearing glasses	π	π
f. Asthma, emphysema, or other chronic lung problem	π	π
g. Liver trouble, such as cirrhosis	π	π
h. Insomnia	π	π
i. Chronic heartburn or ulcers	π	π
j. Deafness or other trouble hearing with one or both ears	π	π
k. Hemorrhoids	π	π
l. Limitation in the use of an arm or leg (missing, paralyzed, or weakness)	π	π
m. Weight problem	π	π
n. Depression	π	π

Acknowledgments: Several of the items in this survey have been adapted, with permission, from the work of colleagues. The following copyrighted items are included: Item 23c from the Trust in Physician Scale, © 1990 Psychological Reports; Items 48-54, from the MOS SF-36 Health Survey, © 1992 Medical Outcomes Trust Inc.; Items 56-57 from the Chronic Conditions Checklist, ©1990 New England Medical Center Hospitals. In addition, items 7b, 8b, 10a, 10b, 13a, 17b and 19a, c, e are modified versions of items referencing similar concepts in the GHAA Consumer Satisfaction Survey, © 1991 GHAA/Davies & Ware.

Measure # 14: National Survey of Children with Special Health Care Needs (CSHCN)

Contact Information:

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Data Resource Center for Child & Adolescent Health
Your Data… Your story

www.childhealthdata.org

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 was not obtained.

Measure # 16a: Medical Home Index – Long Version (MHI-LV)

Contact Information:

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

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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.

CMHI
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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:

www.medicalhomeimprovement.org

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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)

CMHI
Center for Medical Home Improvement

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
Third: When you have selected your Level, please indicate whether *practice* performance within that level is:
"PARTIAL" (some activity within a level) or; ***"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

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).

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 appointments; 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

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

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).

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

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

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

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 informants; 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).

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

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).

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.

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.

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.

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?

Measure # 16b: Medical Home Index – Short Version (MHI-SV)

Contact Information:

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Center for
Medical Home
Improvement

The Medical Home Index in Adult Primary Care Short Version:

Measuring the Organization and Delivery of Primary Care

The Medical Home Index in Adult Primary Care Short Version (MHIAPC-SV)represents ten indicators which have been derived from the Center for Medical Home Improvement's (CMHI) original Medical Home Index in Adult Primary Care (MHIAPC) . This short version can be used as an interval measurement in conjunction with the original MHIAPC ***or*** it can be used as a quick "report card" or snapshot of practice quality. CMHI recommends the use of the full MHIAPC 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 MHIAPC.

The MHIAPC 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 in Adult Primary Care Short Version (MHIAPC-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 primary care.
- Level 2 is pro-active primary care (in addition to Level 1)
- Level 3 illustrates 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".

Measuring the Medical Home in Adult Primary Care Short Version

THEME:	Level 1	Level 2 (in addition to level 1)	Level 3 (in addition to level 2)
#1 Patient/Family Feedback *Requires both MD & key non-MD staff person's perspective.* (#1.5 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Feedback from patients with chronic health conditions regarding their perception/experience 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 for patients with chronic health conditions which helps to identify needs and implement creative solutions; there are tangible supports to enable patients and families/caregivers to participate in this process (e.g. after hours events, transportation, stipends, etc). ☐ PARTIAL ☐ COMPLETE
#2 Cultural Competence (#1.6 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Translation services and materials are available and appropriate for non-English speaking patients with chronic health conditions and/or those with limited literacy; these materials are appropriate to the reading level of the patient and their family or caregiver. ☐ PARTIAL ☐ COMPLETE	Patient assessments include pertinent cultural information, particularly about health beliefs; this information is incorporated into care plans; the *practice* uses these encounters to assess patient and community cultural needs. ☐ PARTIAL ☐ COMPLETE
# 3 Identification of Populations of Patients with Chronic Health Conditions (#2.1 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	A population of patients with chronic health conditions is generated by using a set group of diagnoses; the list is used to enhance care and/or define *practice* activities (e.g. to flag charts and computer databases for special attention or identify a population and its subgroups) ☐ PARTIAL ☐ COMPLETE	Patients with chronic health conditions are identified and documented, problem lists are current, and complexity levels are assigned to each patient; this information creates an accessible *practice* database/patient registry. ☐ PARTIAL ☐ COMPLETE

Measuring the Medical Home in Adult Primary Care Short Version

THEME:	Level 1	Level 2 (in addition to level 1)	Level 3 (in addition to level 2)
# 4 **Care Continuity** (#2.2 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	The team (*PCP*, patient, and staff) develops a plan of care following evidence-based *practices* for patients with chronic health conditions, the plan details visit schedules and communication strategies; home, work and community concerns are addressed in this plan and cross coverage providers are so informed. ☐ PARTIAL ☐ COMPLETE	The *practice*/teams use chronic condition protocols which include goals, services, interventions and referral contacts. A designated care coordinator uses these tools and other standardized office processes to support and engage patients and their families and/or caregivers. ☐ PARTIAL ☐ COMPLETE
#5 **Cooperative Management Between Primary Care Provider *(PCP)* and Specialists** (#2.4 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	The *PCP* and patient set goals for referrals and communicate these to specialists; together they clarify co-management roles among patient, *PCP* and specialists and determine how specialty feedback to the patient and *PCP* supports self management and is explicitly shared. ☐ PARTIAL ☐ COMPLETE	The patient has the option of using the *practice* in a strong coordinating role; patients as partners with the *practice* manage their care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their care). ☐ PARTIAL ☐ COMPLETE

Measuring the Medical Home in Adult Primary Care Short Version

THEME:	Level 2	Level 3	Level 4
#6 **Transitions of care:** From home to hospital; hospital to hospital; hospital to home, nursing home, or rehab; from ER to primary care or home; from one primary care setting to another, etc). (#2.5.1 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Patients with chronic health conditions have a portable written plan of care which includes *practice* contact information and a request for timely updates about any care transitions. The *practice-based care coordinator* communicates with hospital and rehabilitation discharge planners and referring clinics prior to transitions to insure needed resources are in place and follow-up plans are clear. ☐ PARTIAL ☐ COMPLETE	Electronic health information systems are in place to identify and receive real time information about patient access to the health care system and related transitions of care; the *practice* team receives timely transfer of patient information and integrates this knowledge into a full and continuous plan of care (in partnership with the patient and family or care giver). ☐ PARTIAL ☐ COMPLETE
#7 **Care Coordination /Role Definition** (#3.1 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Care coordination activities are based upon ongoing assessments of patient/ family needs; the *practice* partners with the patient to accomplish care coordination goals. ☐ PARTIAL ☐ COMPLETE	*Practice* staff offers a set of care coordination activities (*see page 14), their level of involvement fluctuates according to patient wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring. ☐ PARTIAL ☐ COMPLETE

Measuring the Medical Home in Adult Primary Care Short Version

THEME:	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-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Patients with a chronic health condition, family, and *PCP* review current health status and anticipated problems or needs; they create/revise action plans and allocate shared responsibilities at least 2 times per year or at individualized intervals. ☐ PARTIAL ☐ COMPLETE	The *PCP*/staff and patients create a written plan of care that is monitored at every visit; the office care coordinator is available to the patients and family to implement, update and evaluate the care plan. ☐ PARTIAL ☐ COMPLETE
#9 **Community Assessment of Health Needs** (#4.1 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	Providers raise their own questions regarding the population of patients with chronic health condition in their *practice* communities; they seek pertinent data and information from patients 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 needs assessment about patients with chronic health conditions, integrates results into *practice* policies, and shares conclusions about population needs with community & state agencies. ☐ PARTIAL ☐ COMPLETE
#10 ***Quality* Standards** **(structures)** (#6.1 MHI-Full Adult Primary Care FV)	Adult Primary Care without the elements in levels 2 and 3. ☐ Level 1	The *practice* has its own systematic *quality* improvement structures for patients with chronic health conditions; regular provider and staff meetings are used for input and discussions on how to improve care and treatment for these populations of patients. ☐ PARTIAL ☐ COMPLETE	The *practice* actively utilizes *quality* improvement (QI) processes; staff and patients are supported to participate in these QI activities; resulting *quality* standards are integrated into the operations of the *practice*. ☐ PARTIAL ☐ COMPLETE

Measuring the *Medical Home* in Adult Primary Care
Definitions and Concepts

(Words in *italics* throughout the document are defined below).

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).

Achieving a high *quality medical home* requires:
a) macrosystem support for infrastructure (health systems policy level) and
b) microsystem support for (primary care) *practice* improvement)

Joint Principles of the Patient Centered Primary Care *Medical Home*
Use this link (http://www.pcpcc.net/) to go to the Patient Centered Primary Care Collaborative website to download the consensus document: The Joint Principles of the Patient Centered *Medical Home* (click on patient centered *medical home*) , endorsed by:

The American Academy of Family Physicians (AAFP)
The American Academy of Pediatrics (AAP)
The American College of Physicians (ACP), and
The American Osteopathic Association (AOA)

Measuring the *Medical Home* in Adult Primary Care
Definitions and Concepts

(Words in *italics* throughout the document are defined below).

Practice-Based Care Coordination

Care and services performed in partnership with the patient, family, & caregiver by health professionals to:

1) Establish *patient-centered* community-based "*Medical Homes*" for patients with chronic health conditions and their families.
    - Make assessments and monitor needs
    - Participate in patient/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*, patients and others

3) Build bridges among patients and health, education, social services and employer; promotes continuity of care
    - Develop, monitor, update and follow-up with care planning and care plans
    - Organize team meetings; support meeting recommendations and follow-up

4) Supply/provide access to referrals, information and education for patients and caregivers across systems.
    - Coordinate inter-organizationally
    - Advocate with and for the patient and family (e.g. at work or with 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 patient and *practice*

Measuring the *Medical Home* in Adult Primary Care
Definitions and Concepts

(Words in *italics* throughout the document are defined below).

Chronic Condition Management (CCM):

CCM involves explicit changes in the roles of providers and office staff aimed at improving:

1) Access to needed services
2) Communication with specialists, employers, and other resource supports, and
3) Outcomes for patients, families, *practices*, employers and payers.

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.

Patient –centered care:

Patient-centered, defined by the Institute of Medicine, is providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.

Family-Centered care:

Recognizes that the family is essential to the patient care and is constant in the patient life.

The medical provider acknowledges who the key family members are
The medical provider asks families what they value
Decision-making is shared

Measuring the *Medical Home* in Adult Primary Care
Definitions and Concepts

(Words in *italics* throughout the document are defined below).

Practice:
The place, providers, and staff where the *PCP* offers primary care

Primary Care Provider (PCP):
Physician or nurse practitioner who is considered the main provider of health care for the patient

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.

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?

Measure # 16c: Medical Home Family Index and Survey (MHFIS)

Contact Information:

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

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The Medical Home
Family Index and Survey

CMHI
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Improvement

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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 . . .

Center for
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Improvement

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

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	Never	Sometimes	Often	Always
(If (b) does not apply to your child ✔here ___)				
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	

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*

CMHI
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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
2) Asthma
3) Attention deficit/hyperactivity
4) Autism/pervasive development disorder
5) Blindness/trouble seeing
6) Cerebral palsy
7) Chronic ear infection
8) Cleft lip/palate
9) Cystic fibrosis
10) Deafness/trouble hearing
11) Depression
12) Diabetes
13) Down syndrome
14) Eating disorder
15) Heart disease or heart defect
16) Hemophilia
17) HIV/AIDS
18) Permanent deformity of arms/legs
19) Kidney disease
20) Leukemia/Cancer
21) Mental retardation
22) Muscular dystrophy
23) Obesity
24) Recurrent urinary tract infection
25) Seizure disorder
26) Severe allergies
27) Severe scoliosis
28) Sickle cell disease
29) Spina bifida
30) Other (specify below)

____

____

____

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.______________________________

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

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

11. During the <u>last 3 months</u>, 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 **<u>severity</u>** 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

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 <u>**severity**</u> 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 <u>provided outside of the family</u> 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

25. During the past year, how many separate times did your child have to stay in the hospital overnight?

(1) None at all	(4) 8 - 10 times
(2) 1 - 3 times	(5) More than 10 times
(3) 4 - 7 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	(4) 16 or more work days
(3) 6 - 16 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

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 (<u>not</u> including insurance deductibles or co-payments)?	1	2	DK

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.

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)

Measure # 17a: Primary Care Assessment Tool – Child Expanded Edition (PCAT-CE)

Contact Information:

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

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Copyright Details:

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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:

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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:

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

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- For permission to view and/or use the instrument, please contact the measure developer (contact information listed above).

Measure # 20: Family Medicine Medication Use Processes Matrix (MUPM)

Contact Information:

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

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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					

CONTINUED ON BACK OF PAGE

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					

Contact Barbara Farrell – bfarrell@bruyere.org for more information

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	ف Yes ف No	ف Yes ف No	ف Yes ف No	ف Yes ف No	ف Yes ف No

If you had any difficulty completing certain sections, please state which ones and why:

____

____

____

____

____

~~Other Comments:~~

____

____

____

____

____

~~Please continue to next page.~~

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

Participant ID:

Measure # 21: Resources and Support for Self-Management (RSSM)

Contact Information:

- For questions regarding this measure, contact:

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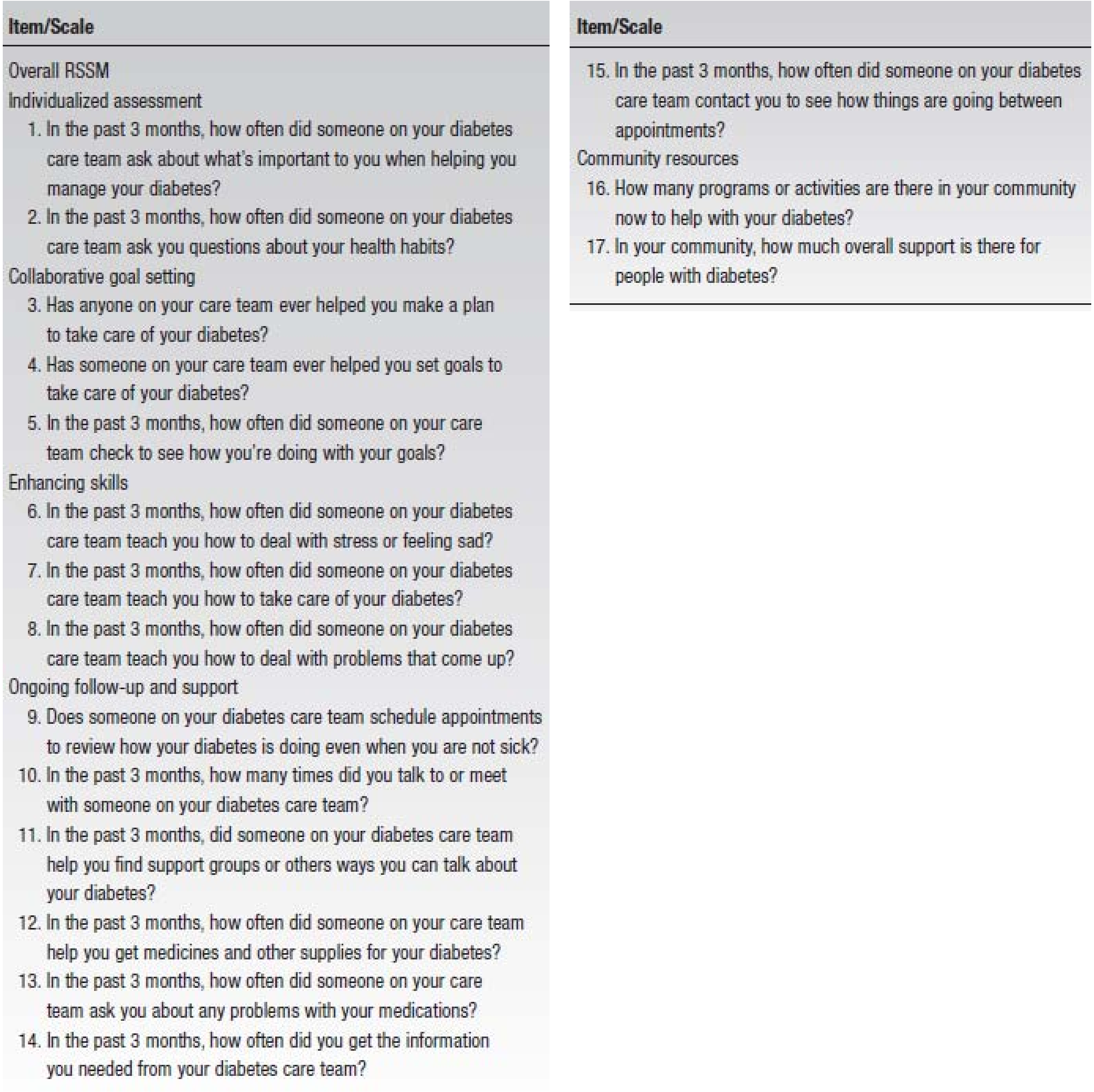
Measure # 21: Resources and Support for Self-Management (RSSM)

The following items were excerpted from Table 2 in the article: Lauren A. McCormack, Pamela A. Williams-Piehota, Carla M. Bann, Joseph Burton, Douglas B. Kamerow, Claudia Squire, Edwin Fisher, Carol A. Brownson and Russell E. Glasgow. Development and validation of an instrument to measure resources for chronic illness self-management: a model using diabetes. *The Diabetes Educator* 34(4), pp.707-18 © 2008 by The Diabetes Educator. Reprinted by Permission of SAGE Publications.



Item/Scale
Overall RSSM
Individualized assessment
1. In the past 3 months, how often did someone on your diabetes care team ask about what's important to you when helping you manage your diabetes?
2. In the past 3 months, how often did someone on your diabetes care team ask you questions about your health habits?
Collaborative goal setting
3. Has anyone on your care team ever helped you make a plan to take care of your diabetes?
4. Has someone on your care team ever helped you set goals to take care of your diabetes?
5. In the past 3 months, how often did someone on your care team check to see how you're doing with your goals?
Enhancing skills
6. In the past 3 months, how often did someone on your diabetes care team teach you how to deal with stress or feeling sad?
7. In the past 3 months, how often did someone on your diabetes care team teach you how to take care of your diabetes?
8. In the past 3 months, how often did someone on your diabetes care team teach you how to deal with problems that come up?
Ongoing follow-up and support
9. Does someone on your diabetes care team schedule appointments to review how your diabetes is doing even when you are not sick?
10. In the past 3 months, how many times did you talk to or meet with someone on your diabetes care team?
11. In the past 3 months, did someone on your diabetes care team help you find support groups or others ways you can talk about your diabetes?
12. In the past 3 months, how often did someone on your care team help you get medicines and other supplies for your diabetes?
13. In the past 3 months, how often did someone on your care team ask you about any problems with your medications?
14. In the past 3 months, how often did you get the information you needed from your diabetes care team?
15. In the past 3 months, how often did someone on your diabetes care team contact you to see how things are going between appointments?
Community resources
16. How many programs or activities are there in your community now to help with your diabetes?
17. In your community, how much overall support is there for people with diabetes?

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:

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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 not 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 (<u>excluding PTSD</u>)?	☐
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 **<u>past 3 months</u>**. Please keep these definitions in mind as you answer the questions.

<u>Intensive inpatient/residential programs</u>- For these programs, the **<u>intensive</u>** 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.

<u>Outpatient programs</u> (e.g., day hospital, intensive outpatient clinic) – For these programs, the **<u>intensive</u>** 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.

<u>Continuing outpatient substance use disorder care</u> – 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:

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Copyright Details:

- The Continuity of Care Practices Survey – Program- and Individual-Level versions (CCPS-P and CCPS-I) are in the public domain and freely available for use without copyright restrictions. The measure developer, Jeanne A. Schaefer, grants permission to the Agency for Healthcare Research and Quality (AHRQ) to print a copy of the measure instrument in the *Care Coordination Measures Atlas* Appendix.
- 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).

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);l 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: Nursing Home Work Environment and Performance Team Survey

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Measure # 24: Measure of Processes of Care (MPOC-28)

Contact Information:

- Contact information unavailable.

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Measure # 25: Care Evaluation Scale for End-of-Life (CES)

Contact Information:

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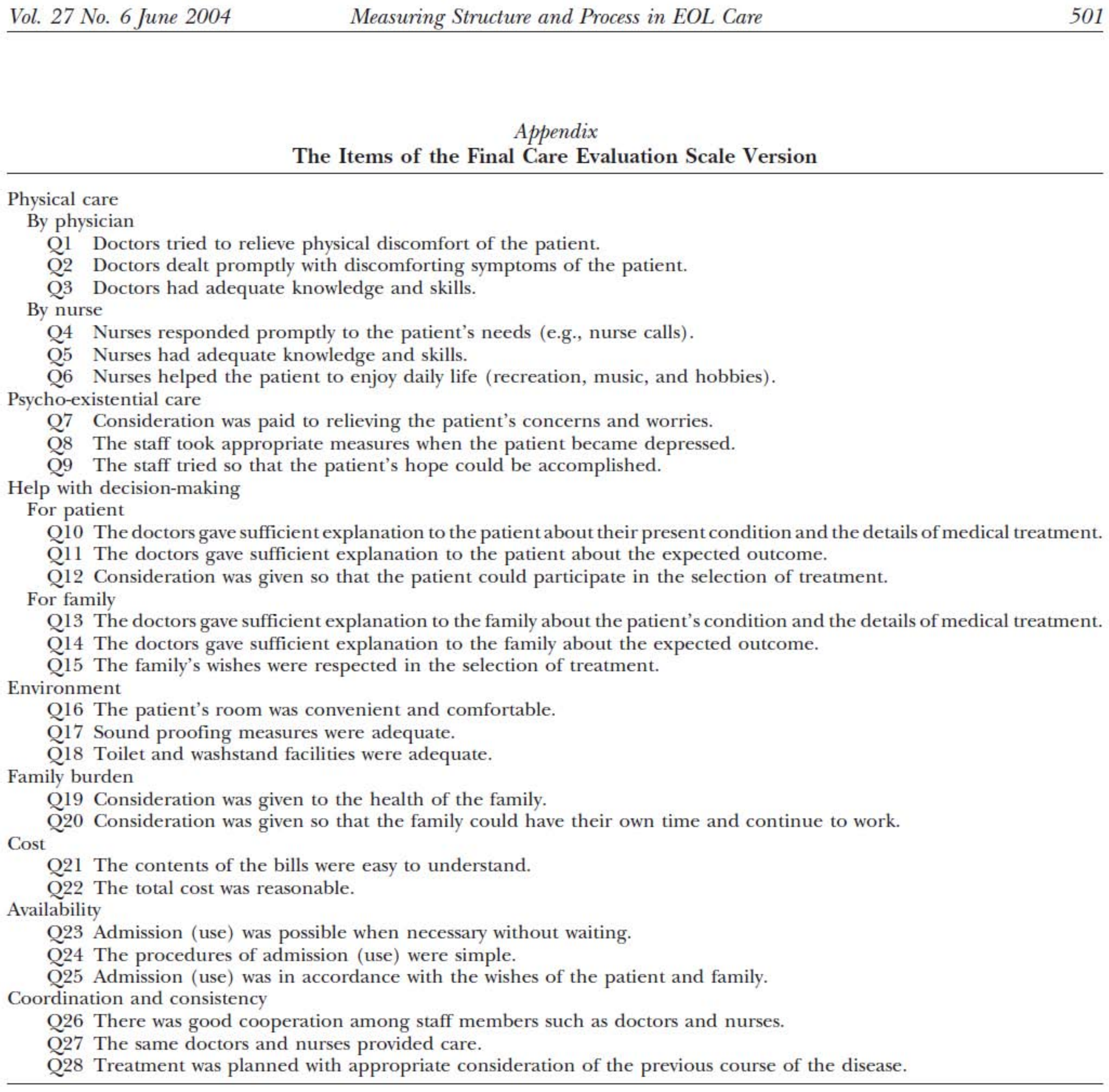

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Appendix

The Items of the Final Care Evaluation Scale Version

Physical care
  By physician
    Q1 Doctors tried to relieve physical discomfort of the patient.
    Q2 Doctors dealt promptly with discomforting symptoms of the patient.
    Q3 Doctors had adequate knowledge and skills.
  By nurse
    Q4 Nurses responded promptly to the patient's needs (e.g., nurse calls).
    Q5 Nurses had adequate knowledge and skills.
    Q6 Nurses helped the patient to enjoy daily life (recreation, music, and hobbies).
Psycho-existential care
    Q7 Consideration was paid to relieving the patient's concerns and worries.
    Q8 The staff took appropriate measures when the patient became depressed.
    Q9 The staff tried so that the patient's hope could be accomplished.
Help with decision-making
  For patient
    Q10 The doctors gave sufficient explanation to the patient about their present condition and the details of medical treatment.
    Q11 The doctors gave sufficient explanation to the patient about the expected outcome.
    Q12 Consideration was given so that the patient could participate in the selection of treatment.
  For family
    Q13 The doctors gave sufficient explanation to the family about the patient's condition and the details of medical treatment.
    Q14 The doctors gave sufficient explanation to the family about the expected outcome.
    Q15 The family's wishes were respected in the selection of treatment.
Environment
    Q16 The patient's room was convenient and comfortable.
    Q17 Sound proofing measures were adequate.
    Q18 Toilet and washstand facilities were adequate.
Family burden
    Q19 Consideration was given to the health of the family.
    Q20 Consideration was given so that the family could have their own time and continue to work.
Cost
    Q21 The contents of the bills were easy to understand.
    Q22 The total cost was reasonable.
Availability
    Q23 Admission (use) was possible when necessary without waiting.
    Q24 The procedures of admission (use) were simple.
    Q25 Admission (use) was in accordance with the wishes of the patient and family.
Coordination and consistency
    Q26 There was good cooperation among staff members such as doctors and nurses.
    Q27 The same doctors and nurses provided care.
    Q28 Treatment was planned with appropriate consideration of the previous course of the disease.

Measure # 26: Oncology Patients’ Perceptions of the Quality of Nursing Care Scale (OPPQNCS)

Contact Information:

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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.

Opening: Please answer the following questions about your nursing care during your last hospitalization.

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 helped me get the information I wanted

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

7. The nurses knew what I had been through

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

8. **The nurses discussed care options with me**

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

9. The nurses knew how to help me when things were bothering me

☐ Always

☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

10. The nurses encouraged me to actively participate in my care

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

11. The nurses told me which nurse was taking over when they were not there

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

12. The nurses arranged for the same nurses to care for me regularly

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

13. The nurses told me which nurse was primarily responsible for coordinating my care

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

14. The nurses gave me accurate explanations about my care

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

15. The nurses knew how to care for someone with my condition

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

16. The nurses were skillful

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

17. The nurses knew what they were doing

☐ Always
☐ Almost Always
☐ Often

☐ Sometimes
☐ Almost Never
☐ Never

18. The nurses knew how to help me

☐ Always
☐ Almost Always
☐ Often
☐ Sometimes
☐ Almost Never
☐ Never

19. In general, how would you describe the quality of the nursing care you received?

☐ Excellent
☐ Good
☐ Fair
☐ Poor

Introduction: Please answer the following questions about your nursing care during your last hospitalization.

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

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

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

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
☐ 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

Contact Information:

- Contact information unavailable.

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Measure # 28: Collaboration and Satisfaction About Care Decisions (CSACD)

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Copyright Details:

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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

Measure # 29: Follow Up Care Delivery

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

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:

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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 *<u>or amount</u>* 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

How are we doing?
Your Opinions about your Family Member's ICU stay

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:

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Additional Notes:

- The measure developer recommended a revised version of the instrument. The following page is a crosswalk to compare the version mapped in the *Care Coordination Measures Atlas* profile to the instrument that follows. The instrument that follows the crosswalk is the revised instrument recommended by the measure developer.

Measure # 31: Korean Primary Care Assessment Tool (KPCAT) Crosswalk

The KPCAT items mapped in the *Atlas* are from Table 2 of the source article: Lee JH, Choi YJ, Sung NJ, et al. Development of the Korean primary care assessment tool: Measuring user experience: Tests of data quality and measurement performance. Int J Quality Health Care 2009; 21(2):103-11. The measure developer recommended a revised version, which follows this page. The numbering of that instrument is different to that in the *Atlas*, therefore we designed the table below to serve as a crosswalk and demonstrate which instrument items were mapped in the *Atlas* profile. Four items from the preliminary tool were removed in the revised instrument reprinted within Appendix IV (items 7, 12, 21, and 22). Of those items, 7 and 21 were mapped. To see those items, please refer to the source article indicated above.

Crosswalk between the KPCAT mapped in the *Care Coordination Measures Atlas* and the KPCAT instrument included in Appendix IV.		
Section	Item as numbered in the revised instrument provided by the measure developer	Instrument numbering as mapped in the *Atlas* measure mapping table
First Contact		
	1	1
	2	2
	3	3
	4	4
	5	5
Comprehensiveness		
	1	8
	2	9
	3	10
	4	11
Coordination		
	1	13
	*	14
	2	15
	3	16
Personalized Care		
	1	6
	2	17
	3	18
	4	19
	5	20
Family/community orientation		
	1	24
	2	23
	3	25
	4	26

Korean Primary Care Assessment Tool

The original instrument is in Korean. The following includes the 21 items of the Korean Primary Care Assessment Tool, which were pulled from Table 2 of the following article: Lee JH, Choi YJ, Sung NJ, et al. Development of the Korean primary care assessment tool: Measuring user experience: Tests of data quality and measurement performance. Int J Quality Health Care 2009; 21(2):103-11.

First Contact.

1. Do you visit this clinic first when a new health problem arises?
2. Is it easy for you to access this facility?
3. Appropriateness of out-of-pocket cost?
4. Your doctor sees patients regardless of their age and sex?
5. Basic health care available?

Comprehensiveness.

1. Medical check-up available? (e.g. physical exam, blood sugar, cholesterol, BP controls, etc.)
2. Counsels for cancer prevention and screening?
3. You (or your family member) get periodic Pap smear tests from your physician?
4. Periodic health examination by your physician?

Coordination.

1. Does your doctor recommend health care resources appropriately?

*Since your doctor started treating you, have you ever visited a specialist?

2. If yes, did your doctor recommend the specialist?
3. If yes, did your doctor review the referral results?

Personalized Care.

1. Does your doctor treat mental health problems as well as physical health problems?
2. Doctor understands patients' words easily?
3. Doctor explains test results in a manner that is easy for patients to understand?
4. Doctor recognizes the importance of the patient's medical history?

5. Trust your doctor’s decisions on treatment?

Family / community orientation.

1. Doctor has a concern about the persons living with you?
2. Doctor knows about the health, well-being and environmental problems of your community?
3. Is the doctor active in promoting the health of your community?
4. This clinic surveys and reflects people’s opinions on health care?

The source article indicates that, “the items have a 5-point Likert-type response format, ranging from 1 (strongly disagree) to 5 (strongly agree), with neutral as the center option…An additional ‘don’t know’ option was included for respondents who wished to answer in this manner, and it was interpreted and regarded as ‘neutral option = 3’. To make the results easier to understand, all scale scores were reduced by a factor of 1 and multiplied by 25 so that they would fall in the range of 0-100 points, with higher scores indicating more favorable performance”.

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:

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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.

Measure # 32: Primary Care Multimorbidity Hassles for Veterans with Chronic Illnesses

The Multimorbidity Hassles Scale mapped in the *Atlas* can be found in the Appendix of the source article: Parchman ML, Hitchcock Noël P, Lee S, et al. Primary care attributes, health care system hassles, and chronic illness. Med Care 2005; 43(11):1123-29. The measure developer provided a more complete version (with two additional items), which follows this page. The numbering of instrument items in the *Atlas* is different to the numbering in the instrument that follows this page. The table below serves as a crosswalk and demonstrates the relationship between instrument items as they were mapped in the *Atlas* measure mapping table and profile.

Crosswalk between the Multimorbidity Hassles Scale mapped in the *Care Coordination Measures Atlas* and the Multimorbidity Hassles Scale included in Appendix IV.

Item as numbered in the instrument provided by the measure developer	Instrument numbering as mapped in the *Atlas* measure mapping table
1	4
2	3
3	5
4	*
5	6
6	*
7	7
8	8
9	9
10	10
11	11
12	12
13	1
14	2[†]
15	13[†]
16	15
17	14
18	16

* - Item not present in the version of the instrument mapped in the *Atlas*.

† - Wording changed slightly between versions; content remains the same.

ABOUT YOUR HEALTHCARE

Please indicate how much each of the following has been a problem for you: (MARK ONE FOR EACH ITEM)

How much of a problem are each of these for you?	Very big problem	Big problem	Moderate Problem	Small Problem	Not a problem at all
(1) Problems getting my medications refilled on time	○	○	○	○	○
(2) Lack of information about why my medications have been prescribed to me	○	○	○	○	○
(3) Uncertainty about when or how to take my medications	○	○	○	○	○
(4) Interactions between my medications	○	○	○	○	○
(5) Side effects from my medications	○	○	○	○	○
(6) Managing multiple medications	○	○	○	○	○
(7) Lack of information about why I've been referred to a specialist	○	○	○	○	○
(8) Having to wait a long time to get an appointment for specialty doctors or clinics	○	○	○	○	○
(9) Poor communication between different doctors or clinics	○	○	○	○	○
(10) Disagreements between my doctors about my diagnoses or the best treatment for me	○	○	○	○	○
(11) Lack of information about why I need lab tests or x-rays	○	○	○	○	○
(12) Having to wait too long to find out about the results of lab tests or x-rays	○	○	○	○	○
(13) Lack of information about my medical conditions	○	○	○	○	○
(14) Lack of information about treatment options or prognosis (chances of getting well)	○	○	○	○	○
(15) Difficulty talking to my doctors between scheduled appointments if I have a question	○	○	○	○	○
(16) Having my concerns ignored or overlooked by my health care providers	○	○	○	○	○
(17) Lack of time to discuss all my problems with my health care provider during scheduled appointments	○	○	○	○	○
(18) Medical appointments that interfere with my work, family, or hobbies	○	○	○	○	○

Measure # 33: Primary Care Satisfaction Survey for Women (PCSSW)

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

Measure # 34: Personal Health Records (PHR)

Contact Information:

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Personal Health Record (PHR) Issues Interview Questions:

Measure items pulled from Table 1 in: Reti SR, Feldman HJ, Ross SE, et al. Improving personal health records for patient-centered care. JAMIA 2010; 17:192-5.

1. Can patients authorize another person(s) as a proxy for PHR access?
2. Are minors able to access their PHR?
3. Are patients able to view full EMR clinical progress notes?
4. Can patients view an EMR full diagnosis list?
5. Can patients control who sees what PHR data?
6. Is patient self-entered PHR data able to be used for research purposes?
7. Does 3rd party health related web based advertising occur on the PHR website?
8. Is there a "break the glass" function allowing PHR information to be available in emergencies?
9. From when normal laboratory results are available to clinicians, how soon are they available to PHR?
10. What is the policy timeframe for clinicians to respond to patient PHR emails?

EMR = electronic medical record
PHR = personal health record

Measure # 35: Picker Patient Experience (PPE-15)

Contact Information:

- Contact information unavailable.

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The Picker Patient Experience (PPE-15)

Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: Development and validation using data from in-patient surveys in five countries. Int J Qual Health Care 2002; 14(5):353-58, by permission of Oxford University Press.

The text that follows was pulled directly from the Appendix of the source article indicated above.

1. When you had important questions to ask a doctor, did you get answers that you could understand?

   Yes, always   Yes, sometimes   No   I had no need to ask

2. When you had important questions to ask a nurse, did you get answers that you could understand?

   Yes, always   Yes, sometimes   No   I had no need to ask

3. Sometimes in a hospital, one doctor or nurse wills ay one thing and another will say something quite different. Did this happen to you?

   Yes, often   Yes, sometimes   No

4. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?

   Yes, completely   Yes, to some extent   No   I didn't have any anxieties or fears

5. Did doctors talk in front of you as if you weren't there?

   Yes, often   Yes, sometimes   No

6. Did you want to be more involved in decisions made about your care and treatment?

   Yes, definitely   Yes, to some extent   No

7. Overall, did you feel you were treated with respect and dignity while you were in hospital?

   Yes, always   Yes, sometimes   No

8. If you had any anxieties or fears about your condition or treatment, did a nurse discuss them with you?

   Yes, completely   Yes, to some extent   No   I didn't have any anxieties or fears

9. Did you find someone on the hospital staff to talk to about your concerns?

   Yes, completely   Yes, to some extent   No   I had no concerns

10. Were you ever in pain?

Yes No

If yes…

a. Do you think the hospital staff did everything they could to help control your pain?

Yes, definitely Yes, to some extent No

11. If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?

Yes, definitely Yes, to some extent No No family or friends were involved

My family didn't want or need information I didn't want my family or friends to talk to a doctor

12. Did the doctors or nurses give your family or someone else close to you all the information they needed to help you recover?

Yes, definitely Yes, to some extent No No family or friends were involved

My family didn't want or need information

13. Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?

Yes, completely Yes, to some extent No I didn't need an explanation
I had no medicines ---------------------- Go to question 15

14. Did a member of staff tell you about medication side effects to watch for when you went home?

Yes, completely Yes, to some extent No I didn't need an explanation

15. Did someone tell you about danger signals regarding your illness or treatment to watch for after you went home?

Yes, definitely Yes, to some extent No

Measure # 36: Physician Office Quality of Care Monitor (QCM)

Contact Information:

- Contact information unavailable.

Copyright Details:

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Measure # 37: Patient Perceptions of Care (PPOC)

Contact Information:

- Contact information unavailable.

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Measure # 38a: PREPARED Survey – Patient Version

Contact Information:

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

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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

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University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

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)? : ____

   ____

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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	○
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	○
3	Were you given **written** instructions about your medications? *Please tick only one box*	Yes	○
		No	○
		Not taking **any** medications	○
4	If **YES** did someone spend time explaining the written instructions? *Please tick only one box*	Yes	○
		No	○
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	○
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	○
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	○

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 ○
No ○
No-one needed to:- Services were already in place ○
No-one needed to: No services needed ○

1a. If you answered **YES**, have the services commenced? ***or*** If you answered **SERVICES WERE ALREADY IN PLACE**, have the services recommenced?

Yes ○
No ○

1b. If **NO**, why? ……………………………………………………………………………………………

……………………………………………………………………………………………

---

2. Did anyone arrange equipment for you?
Please tick only one box

Yes ○
No ○
No-one needed to:- Equipment already in place ○
No-one needed to: No equipment needed ○

2a. If **YES**, do you have this equipment now?

Yes ○
No ○

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 ○
No ○

3a. Please tell us more about this

………

………

Section IV: After the patient was told he/she could leave hospital:

1 How confident did **<u>you</u>** feel about managing at home?
Please tick only one box

Confident ○
Unsure ○
Not confident ○

Please tell us more about this

……

……

2 Were there any delays on the day you left hospital?
Please tick

Yes ○
No ○

3. If **YES,** what were the delays?
Please tick as many as you wish

Transport ○
Medications ○
Don’t know ○
Other ○

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 ○
No ○

1a. Please tell us more about this

……

……

---

2 Has anything been done to deal with your worries?
Please tick

Yes ○
No ○

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 ○

No ○

---

4. Have any unexpected problems occurred since you have been home?

Please tick

Yes ○

No ○

4a. Please tell us more about this

……

……

---

5. If the you have already received community services, have these services met your needs?…

Please tick

Yes ○

No ○

Everyone = you, the patient and any one else involved

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 ○

No ○

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
Physiotherapist
Occupational Therapist
Domiciliary Care
District Nurse
Hospital outpatient/ Emergency clinic

Your specialist doctor
Chemist
Meals on Wheels
Other health professionals
Any other people who have helped you
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 ○
Assistance with shopping ○
House cleaning ○
Other (Please indicate): ○
………………………………………………

---

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 $
Extra shopping $
Extra chemist costs $
Other

Petrol $
Gap payments for health services $
Private Health Services $
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 ○
No ○

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 ○

Moderately prepared ○

Unprepared ○

---

2. Were there any particular aspects of your preparation for discharge <u>whilst in hospital</u>, that you would like to further comment on?

……

……

……

……

……

……

---

3. Were there any particular aspects of the patient’s care <u>after leaving hospital</u> 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 ○

No ○

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 ○

No ○

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
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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

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University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

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** ○ **No** ○

7. Do you live at the same address as the patient?

   Please tick: **Yes** ○ **No** ○

Instrument Authors
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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
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
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 ○
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 ○
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 ○

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 No No-one needed to:- Services were already in place No-one needed to: No services needed	○ ○ ○ ○
	If you answered **YES**, have the services commenced? ***or*** If you answered **SERVICES WERE ALREADY IN PLACE**, have the services recommenced?	Yes No	○ ○
2.	Did anyone arrange equipment for the patient? *Please tick only one box*	Yes No No-one needed to:- Equipment already in place No-one needed to: No equipment needed	○ ○ ○ ○
	If **YES**, does the patient have this equipment now?	Yes No	○ ○
3.	Did anyone talk to **you** about how **you** would manage **your** usual duties while caring for the patient? (*e.g. shopping, showering, bathing, dressing, toileting, feeding, mobility, transportation*) *Please tick correct box*	Yes No	○ ○
4.	Did you receive advice about services available for carers themselves? (eg carer respite services)	Yes No *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 ○
Unsure ○
Not confident ○

1a. Please tell us more about this

……

……

……

……

2 Were there any delays in the patient leaving hospital?
Please tick

Yes ○
No ○

2a. If **YES,** what were the delays?
Please tick as many as you wish

Transport ○
Medications ○
Don’t know ○
Other ○

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 ○
No ○

1a. Please tell us more about this

……

……

---

2 Has anything been worrying **you** about managing the patient at home? *Please tick*

Yes ○
No ○

2a. Please tell us more about this

………

………

---

3 Has anything been done to deal with your worries?

Please tick

Yes ○

No ○

3a. Please tell us more about this

………

………

---

4. Have any unexpected problems occurred since the patient left hospital to make **<u>you</u>** feel less confident about managing?

Please tick

Yes ○

No ○

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 ○

No ○

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 ○

No ○

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

Physiotherapist

Occupational Therapist

Domiciliary Care

District Nurse

Hospital outpatient/ Emergency clinic

Your specialist doctor

Chemist

Meals on Wheels

Other health professionals

Any other people who have helped you

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 ○
No ○

2a. If so, what are these costs approximately?

Taxi fares $

Extra shopping $

Extra chemist costs $

Other

Petrol $

Gap payments for health services $

Private Health Services $

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 ○
No ○

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 ○
Could have been better prepared ○
Unprepared ○

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:

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  Director, International Centre for Allied Health Evidence (iCAHE)
  City East Campus, University of South Australia
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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

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University of South Australia
GPO Box 2471
Adelaide SA 5001
Australia

CRICOS Provider Number
001218

CAHE
University of South Australia
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*

____

____

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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:
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  City East Campus, University of South Australia
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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

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Adelaide SA 5001
Australia

CRICOS Provider Number
001218

CAHE
University of South Australia
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	☐

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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:
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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 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 ☐

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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

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?

____

____

____

____

____

____

____

____

____

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____

____

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:

- For questions regarding this measure and for permission to use it, contact:
  James F. Graumlich, MD FACP
  Associate Professor of Medicine and Clinical Pharmacology
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- Any use of the measure instruments must be accompanied by the following citation: Graumlich JF, Novotny NL, Aldag JC. Brief scale measuring patient preparedness for hospital discharge to home: psychometric properties. J Hosp Med 2008; 3(6): 455-464. The measure owner requests that users send a copy of any modifications or alterations made to the instrument to James F. Graumlich (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

Appendix:

WHILE YOU WERE IN HOSPITAL:

Item	Question	Response options
1	How much information did you receive about the medications that you were to take home?	As much as I needed Some, but not enough None Not taking **any** medications
2	How much information did you receive about the side effects of the medications that you were to take at home?	As much as I needed Some, but not enough None Not taking **any** medications
3	Were you given **written** instructions about your medications?	Yes No Not taking **any** medications
3a	If **YES** did someone spend time explaining the written instructions?	Yes No
4	How much information did you receive on how you would **manage your usual activities** when you went home? *(e.g. shopping, showering, bathing etc*	As much as I needed Some, but not enough None
5	How much information did you receive on **community services** you might use once you went home? (*e.g. Home Health Care, Home Health Nurse, Meals on Wheels etc)*	As much as I needed Some, but not enough None No services needed

6	How much information did you receive on **<u>equipment</u>** you might need once you went home? (*e.g. rails, shower chair, walking aids etc)*	As much as I needed Some, but not enough None No equipment needed

BEFORE YOU WERE DISCHARGED FROM HOSPITAL:

Item	Question	Response options
7	Did anyone arrange community services for you to use at home? (*e.g. Home Health Care, Home Health Nurse, Meals on Wheels etc)*	Yes No No one needed to: services were already in place No one needed to: no services needed
8	Did anyone arrange equipment for you?	Yes No No one needed to: Equipment already in place No one needed to: No equipment needed
9	Was there any other information you would have liked while you were in hospital, to prepare you for coping at home?	Yes No

AFTER YOU WERE TOLD YOU COULD LEAVE HOSPITAL:

Item	Question	Response options
10	How confident did you feel about managing at home?	Confident Unsure Not confident
12	Were there any delays on the day you left the hospital?	Yes No

NOW THAT YOU HAVE BEEN OUT OF HOSPITAL FOR A WHILE:

Item	Question	Response options
13	Has anything been worrying you about managing at home?	Yes No

LOOKING BACK TO THE TIME YOU LEFT HOSPITAL:

Item	Question	Response options
11	Overall, how prepared did you feel for returning home?	Very prepared Moderately prepared Unprepared

Measure # 39: Health Tracking Household Survey

Contact Information:

- Contact information unavailable.

Copyright Details:

- The measure instrument is in the public domain. The measure developer requests the proper citation of The Center for Studying Health System Change (HSC), with funding by the Robert Wood Johnson Foundation (RWJF). The Household Survey is available from: http://www.hschange.org/CONTENT/1091/

Measure # 40: Adapted Picker Institute Cancer Survey

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

Measure # 41: Ambulatory Care Experiences Survey (ACES)

Contact Information:

- Requests and questions related to the Ambulatory Care Experiences Survey (ACES) can be made by following the link: http://160.109.101.132/icrhps/resprog/thi/aces.asp.

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AMBULATORY CARE EXPERIENCES SURVEY – SHORT FORM (PCP)

YOUR PERSONAL DOCTOR

1. Our records show that your regular personal doctor is:

<docname>

Is that correct?

○ Yes ➔ ***Go to Question 2***
○ No, my personal doctor is: __________________________ ➔ Go to Question 2. (Please write correct name of your doctor.)
○ No, I do not have a personal doctor. ➔ ***Go to Question 28 on Page 4***

2. How long has this person been your personal doctor?

○ Less than 6 months
○ Between 6 months and 1 year
○ 1 to 2 years
○ 3 to 5 years
○ More than 5 years

3. In the last 12 months, have you had any visits with your personal doctor?

○ Yes ➔ ***Go to Question 4***
○ No ➔ ***Go to Question 28 on Page 4***

SCHEDULING APPOINTMENTS AND SEEING A DOCTOR

4. In the last 12 months, when you needed care for an illness or injury, how often did your personal doctor's office provide care as soon as you needed it?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always
○ I did not need care for an illness or injury in the last 12 months.

5. In the last 12 months, when you scheduled an appointment for a check-up or routine care, how often did you get an appointment as soon as you needed it?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost Always
○ Always
○ I did not schedule any check-ups or routine care in the last 12 months.

6. In the last 12 months, when you called your personal doctor's office with a medical question during regular office hours, how often did you get an answer that same day?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost Always
○ Always
○ I did not call my personal doctor's office during office hours in the last 12 months.

7. In the last 12 months, when you called your personal doctor's office after regular office hours, how often did you get the help or advice you needed?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost Always
○ Always
○ I did not call my personal doctor's office after regular office hours in the last 12 months.

8. In the last 12 months, how often were office staff at your personal doctor's office as helpful as you thought they should be?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

MANAGING YOUR CARE

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

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

10. In the last 12 months, how often did your personal doctor listen carefully to you?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

11. In the last 12 months, how often did your personal doctor give you clear instructions about what to do to take care of the health problems or symptoms that were bothering you?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

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

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

13. In the last 12 months, did your personal doctor recommend a treatment for a health problem or symptom that was bothering you?

○ Yes
○ No

14. In the last 12 months, did your personal doctor ever say that there was more than one treatment option to consider for your care?

○ Yes ➔ ***Go to Question 15***
○ No ➔ ***Go to Question 17***

15. In the last 12 months, when there was more than one treatment option to consider, did your personal doctor give you enough information about each option?

○ Yes, definitely
○ Yes, somewhat
○ No, definitely not

16. In the last 12 months, when there was more than one treatment option to consider, did your personal doctor ask you which treatment option you preferred?

○ Yes, definitely
○ Yes, somewhat
○ No, definitely not

17. In the last 12 months, did your personal doctor give you the help you needed to make changes in your habits or lifestyle that would improve your health or prevent illness?

- ○ Yes, definitely
- ○ Yes, somewhat
- ○ No, definitely not
- ○ I did not need help with this.

18. In the last 12 months, how often did your personal doctor spend enough time with you?

- ○ Never
- ○ Almost never
- ○ Sometimes
- ○ Usually
- ○ Almost always
- ○ Always

19. In the last 12 months, how often did you feel you could tell your personal doctor anything, even things that you might not tell anyone else?

- ○ Never
- ○ Almost never
- ○ Sometimes
- ○ Usually
- ○ Almost always
- ○ Always

20. How would you rate your personal doctor's knowledge of your medical history?

- ○ Very poor
- ○ Poor
- ○ Fair
- ○ Good
- ○ Very good
- ○ Excellent

COORDINATING YOUR CARE

21. In the last 12 months, how often did your personal doctor seem informed and up-to-date about the care you received from specialist doctors?

- ○ Never
- ○ Almost never
- ○ Sometimes
- ○ Usually
- ○ Almost always
- ○ Always
- ○ I did not see any specialist doctors in the last 12 months.

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

- ○ Yes, always
- ○ Yes, sometimes
- ○ No, never
- ○ My personal doctor did not send me for any medical tests in the last 12 months.

OVERALL RATING

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

- ○ 0 Worst personal doctor possible
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7
- ○ 8
- ○ 9
- ○ 10 Best personal doctor possible

24. Would you recommend your personal doctor to your family and friends?

- ○ Definitely yes
- ○ Probably yes
- ○ Not sure
- ○ Probably not
- ○ Definitely not

OTHER DOCTORS OR NURSES

25. Are there other doctors or nurses in your personal doctor's office who you have seen for any of your visits in the last 12 months?

○ Yes ➔ ***Go to Question 26***
○ No ➔ ***Go to Question 28***

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

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

27. In the last 12 months, how often did these other doctors or nurses spend enough time with you?

○ Never
○ Almost never
○ Sometimes
○ Usually
○ Almost always
○ Always

ABOUT YOU

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

○ Excellent
○ Very good
○ Good
○ Fair
○ Poor

29. In what year were you born?

☐ ☐ ☐ ☐ Year (Write in)

30. Are you male or female?

○ Male
○ Female

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

○ 8th grade or less
○ Some high school, but did not graduate
○ High school graduate or GED
○ Some college or 2-year degree
○ 4-year college graduate
○ More than 4-year college degree

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

○ Hispanic or Latino
○ Not Hispanic or Latino

33. Which of the following best describes your race?

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

34. Has a doctor ever told you that you had:

		Yes	No
a.	Hypertension or high blood pressure	○	○
b.	Angina or coronary artery disease	○	○
c.	Congestive heart failure	○	○
d.	Diabetes	○	○
e.	Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease)	○	○
f.	Rheumatoid Arthritis, Osteoarthritis, or DJD	○	○
g.	Any cancer (other than skin)	○	○
h.	Depression	○	○
i.	Acid reflux or stomach ulcers	○	○
j.	Migraine headaches	○	○

Thank you.

When you are done, please use the enclosed prepaid envelope to mail the questionnaire to:

ADDRESS

Several items in this survey have been adapted from the following previously validated survey instruments: Ambulatory Care Experiences Survey © 2002-2003 New England Medical Center Hospitals, Inc./Massachusetts Health Quality Partners; CAHPS® 2.0 Adult Core Questionnaire 1998 Agency for Healthcare Research and Policy; PCAS © 1996-1999 New England Medical Center Hospitals, Inc.

Measure # 42: Patient Perception of Continuity Instrument (PC)

Contact Information:

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

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Cleveland, OH 44106
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Copyright Details:

-

1. PLEASE USE 1 THROUGH 5 TO INDICATE HOW TRUE OR FALSE YOU FEEL EACH OF THE FOLLOWING STATEMENTS IS:

DEFINITELY TRUE	MOSTLY TRUE	UNCERTAIN	MOSTLY FALSE	DEFINITELY FALSE
1	2	3	4	5

A. If more than one family member needs medical care, we go to different doctors.

B. My doctor often mentions or refers to my past medical problems and treatments.

C. I receive my medical care at more than one location.

D. The doctor has a list of all the medicines which I am taking now.

E. I rarely see the same doctor when I go for medical care.

F. My medical care improves when the doctor has seen me before.

G. I have medical problems that the doctor doesn't know about.

H. My doctor provides care for any type of problem which I may have.

2. PLEASE INDICATE YOUR OPINION OF THE FOLLOWING STATEMENTS, USING:

AGREE STRONGLY	AGREE	UNCERTAIN	DISAGREE	DISAGREE STRONGLY
1	2	3	4	5

A. I feel that I have an on-going relationship with a doctor.

B. It is difficult to bring up unrelated medical problems with the doctor.

C. I am uncomfortable in discussing a personal problem with the doctor.

D. The doctor knows a lot about the rest of my family.

E. I feel comfortable asking questions of the doctor.

F. The doctor doesn't know about my family problems.

G. The doctor does not explain things to me.

H. In an emergency, I want my regular doctor to see me.

I. I would rather see another doctor right away, instead of waiting a day or two to see my regular doctor.

J. My doctor provides appropriate referrals to other specialists.

K. My doctor would take care of me if I had to go to the hospital.

L. My doctor would take care of me if I require emergency care.

M. I trust a specialist recommended by my doctor.

N. My doctor would know me by name if we met on the street.

O. I trust my doctor.

Scoring:

The scores for items 1B, 1D, 1F, 1H, 2A, 2D, 2E, 2H, 2J, 2K, 2L, 2M, 2N, and 2O are reversed by subtracting from six to convert them, so higher score indicates greater continuity.

Equal weight is given to each item.

The mean score for the 23 items is calculated.

A higher score indicates greater perception of continuity.

Measure # 43: Jefferson Scale of Attitudes Toward Physician-Nurse Collaboration (JSAPNC)

Contact Information:

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

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JEFFERSON SCALE OF ATTITUDES TOWARD PHYSICIAN-NURSE COLLABORATION

INSTRUCTIONS: Please indicate the extent of your ***agreement*** or ***disagreement*** with each of the following statements by circling the appropriate number. For the purposes of this survey, a nurse is defined as "a registered nurse (RN) who is engaged in providing or directly supervising the care of hospitalized patients."

Gender: [1] Male. [2] Female. **Age** (in years): ____

You are a: [1] **Nurse** (Please specify your degree: ____________Your specialization: ______________________).
[2] **Physician** (Please specify your primary specialty: ____).

		Strongly Agree	Tend to Agree	Tend to Disagree	Strongly Disagree
1.	A nurse should be viewed as a collaborator and colleague with a physician rather than his/her assistant….	4	3	2	1
2.	Nurses are qualified to assess and respond to psychological aspects of patients' needs…………………….	4	3	2	1
3.	During their education, medical and nursing students should be involved in teamwork in order to understand their respective roles………………………………………………………………………..	4	3	2	1
4.	Nurses should be involved in making policy decisions affecting their working conditions………………..	4	3	2	1
5.	Nurses should be accountable to patients for the nursing care they provide………………………………..	4	3	2	1
6.	There are many overlapping areas of responsibility between physicians and nurses………………………..	4	3	2	1
7.	Nurses have special expertise in patient education and psychological counseling…………………………..	4	3	2	1
8.	Doctors should be the dominant authority in all health care matters………………………………………..	4	3	2	1
9.	Physicians and nurses should contribute to decisions regarding the hospital discharge of patients………..	4	3	2	1
10.	The primary function of the nurse is to carry out the physician's orders……………………………………	4	3	2	1
11.	Nurses should be involved in making policy decisions concerning the hospital support services upon which their work depends…………………………………………………………………………….	4	3	2	1
12.	Nurses should also have responsibility for monitoring the effects of medical treatment……………………	4	3	2	1
13.	Nurses should clarify a physician's order when they feel that it might have the potential for detrimental effects on the patient………………………………………………………………………………………	4	3	2	1
14.	Physicians should be educated to establish collaborative relationships with nurses………………………..	4	3	2	1
15.	Interprofessional relationships between physicians and nurses should be included in their educational programs…………………………………………………………………………………………...	4	3	2	1

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

Copyright Details:

-

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 following 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.

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?

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?

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?

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.

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?

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?

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?

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?

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 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?

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.

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?

Measure # 44: Clinical Microsystem Assessment Tool (CMAT)

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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.

CLINICAL MICROSYSTEM ASSESSMENT TOOL

Instructions: Each of the "success" characteristics (e.g., leadership) is followed by a series of three descriptions. For each characteristic, ***please check*** the description that ***best describes*** your current microsystem and the care it delivers *OR* use a microsystem you are *MOST* familiar with.

	Characteristic and Definition	Descriptions			
Leadership	**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.	☐ Leaders often tell me how to do my job and leave little room for innovation and autonomy. Overall, they don't foster a positive culture.	☐ Leaders struggle to find the right balance between reaching performance goals and supporting and empowering the staff.	☐ Leaders maintain constancy of purpose, establish clear goals and expectations, and foster a respectful positive culture. Leaders take time to build knowledge, review and reflect, and take action about microsystems and the larger organization.	☐ Can't Rate
	2. Organizational Support: The larger organization looks for ways to support the work of the microsystem and coordinate the hand-offs between microsystems.	☐ The larger organization isn't supportive in a way that provides recognition, information, and resources to enhance my work.	☐ The larger organization is inconsistent and unpredictable in providing the recognition, information and resources needed to enhance my work.	☐ The larger organization provides recognition, information, and resources that enhance my work and makes it easier for me to meet the needs of patients.	☐ Can't Rate
Staff	**3. Staff Focus:** There is selective hiring of the right kind of people. The orientation process is designed to fully integrate new staff into culture and work roles. Expectations of staff are high regarding performance, continuing education, professional growth, and networking.	☐ I am not made to feel like a valued member of the microsystem. My orientation was incomplete. My continuing education and professional growth needs are not being met.	☐ I feel like I am a valued member of the microsystem, but I don't think the microsystem is doing all that it could to support education and training of staff, workload, and professional growth.	☐ I am a valued member of the microsystem and what I say matters. This is evident through staffing, education and training, workload, and professional growth.	☐ Can't Rate
	4. Education and Training: All clinical microsystems have responsibility for the ongoing education and training of staff and for aligning daily work roles with training competencies. Academic clinical microsystems have the additional responsibility of training students.	☐ 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" to what we do.	☐ 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.	☐ There is a team approach to training, whether we are are training staff, nurses or students. Education and patient care are integrated into the flow of work in a way that benefits both from the available resources. Continuing education for all staff is recognized as vital to our continued success.	☐ Can't Rate
	5. Interdependence: The interaction of staff 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.	☐ I work independently and I am responsible for my own part of the work. There is a lack of collaboration and a lack of appreciation for the importance of complementary roles.	☐ The care approach is interdisciplinary, but we are not always able to work together as an effective team.	☐ Care is provided by a interdisciplinary team characterized by trust, collaboration, appreciation of complementary roles, and a recognition that all contribute individually to a shared purpose.	☐ Can't Rate
Patients	**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 smooth service flow.	☐ Most of us, including our patients, 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 more effectively and consistently learning about and meeting patient needs.	☐ We are effective in learning about and meeting patient needs — caring, listening, educating, and responding to special requests, and smooth service flow.	☐ Can't Rate

Side A

Please continue on Side B

CLINICAL MICROSYSTEM ASSESSMENT TOOL

- CONTINUED -

	Characteristic and Definition		Descriptions			
Patients	**7. Community and Market Focus:** The microsystem is a resource for the community; the community is a resource to the microsystem; the microsystem establishes excellent and innovative relationships with the community.		☐ We focus on the patients who come to our unit. 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.	☐ Can't Rate
Performance	**8. Performance Results:** Performance focuses on patient outcomes, avoidable costs, streamlining delivery, using data feedback, promoting positive competition, and frank discussions about performance.		☐ We don't routinely collect data 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 processes of care.	☐ Outcomes (clinical, satisfaction, financial, technical, safety) are routinely measured, we feed data back to staff, and we make changes based on data.	☐ Can't Rate
	9. Process Improvement: An atmosphere for learning and redesign is supported by the continuous monitoring of care, use of benchmarking, frequent tests of change, and a staff that has been empowered to innovate.		☐ The resources required (in the form of training, financial support, 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.	☐ There are ample resources to support continual improvement work. Studying, measuring and improving care in a scientific way are essential parts of our daily work.	☐ Can't Rate
Information and Information Technology	**10. Information and Information Technology:** Information is THE connector - staff to patients, staff to staff, needs with actions to meet needs. Technology facilitates effective communication and multiple formal and informal channels are used to keep everyone informed all the time, listen to everyone's ideas, and ensure that everyone is connected on important topics. *Given the complexity of information and the use of technology in the microsystem, assess your microsystem on the following three characteristics: (1) integration of information with patients, (2) integration of information with providers and staff, and (3) integration of information with technology.*	A. Integration of Information with Patients	☐ Patients have access to some standard information that is available to all patients.	☐ Patients have access to standard information that is available to all patients. We've started to think about how to improve the information they are given to better meet their needs.	☐ Patients have a variety of ways to get the information they need and it can be customized to meet their individual learning styles. We routinely ask patients for feedback about how to improve the information we give them.	☐ Can't Rate
		B. Integration of Information with Providers and Staff	☐ I am always tracking down the information I need to do my work.	☐ Most of the time I have the information I need, but sometimes essential information is missing and I have to track it down.	☐ The information I need to do my work is available when I need it.	☐ Can't Rate
		C. Integration of Information with Technology	☐ The technology I need to facilitate and enhance my work is either not available to me or it is available but not effective. The technology we currently have does not make my job easier.	☐ I have access to technology that will enhance my work, but it is not easy to use and seems to be cumbersome and time consuming.	☐ Technology facilitates a smooth linkage between information and patient care by providing timely, effective access to a rich information environment. The information environment has been designed to support the work of the clinical unit.	☐ Can't Rate

Measure # 45: Components of Primary Care Index (CPCI)

Contact Information:

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Measure # 46: Relational Coordination Survey (RCS)

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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

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

Measure # 48: After Death Bereaved Family Member Interview

Contact Information:

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TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Nursing Home Version

August 2000

CONTENTS AT A GLANCE

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.]

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.

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 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.

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

○ ① 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.

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

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)

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 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
[ ] 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)

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)

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)

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.

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

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

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?
①

[ ] 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?
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 in 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

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

These next questions are about <u>your</u> 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?

DC

- [ ] 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?

①

- [ ] 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 <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

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]

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) <u>symptoms were controlled</u> 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] <u>died with dignity</u> - 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 <u>providing emotional support</u> 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]

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

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?

- [ ] 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 ***********

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

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?

[ ] 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]

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

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.

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

☺

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?

①

[ ] 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?

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

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?

①

[ ] 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 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

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 ***********

TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Hospital Version

August 2000

CONTENTS AT A GLANCE

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 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.

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 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.

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

○ ① 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.

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

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]?

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 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

[ ] 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

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

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

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.

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

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

(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?

[ ] 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?

[ ] 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

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?

D C

[ ] 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?

①

[ ] 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

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 <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 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

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] <u>communicate</u> with (him/her) and the family about the illness and the likely outcomes of care?

[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 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]

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

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?

[ ] 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 ***********

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

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?

[ ] 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]

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.

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)

[ ] 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?

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 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 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?

①

[ ] 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

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

********** THANK RESPONDENT AND TERMINATE INTERVIEW ***********

TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE

AFTER-DEATH BEREAVED FAMILY MEMBER INTERVIEW

Hospice Version

August 2000

CONTENTS AT A GLANCE

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 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.

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.

- 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.

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

○ ① 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

○ DC 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.

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

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)

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 your 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 in [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 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

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

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

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

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?

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

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
[ ] 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

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

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?

①

[ ] 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 <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 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 [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] 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 hospice), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

R

[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 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]

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

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?

[ ] 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 ***********

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

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?

- ☐ 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]

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 <u>you</u> 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.

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

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

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

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?

①

[ ] 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 <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 ***********

Measure # 49: Schizophrenia Quality Indicators for Integrated Care

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

Measure # 50: Degree of Clinical Integration Measures

Contact Information:

- Contact information unavailable.

Copyright Details:

- Permission to reprint a copy of the instrument was not obtained.

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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Data Resource Center for Child & Adolescent Health
Your Data… Your story

www.childhealthdata.org

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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APPENDIX B. AACVPR/ACCF/AHA 2010 UPDATE: PERFORMANCE MEASURES ON CARDIAC REHABILITATION FOR REFERRAL TO CARDIAC REHABILITATION/SECONDARY PREVENTION SERVICES

Performance Measure A-1

A-1. Cardiac Rehabilitation Patient Referral From an Inpatient Setting

All patients hospitalized with a primary diagnosis of an acute myocardial infarction (MI) or chronic stable angina (CSA), or who during hospitalization have undergone coronary artery bypass graft (CABG) surgery, a percutaneous coronary intervention (PCI), cardiac valve surgery, or cardiac transplantation are to be referred to an early outpatient cardiac rehabilitation/secondary prevention (CR) program.

Numerator	Number of eligible patients with a qualifying event/diagnosis who have been referred to an outpatient CR program prior to hospital discharge or have a documented medical or patient-centered reason why such a referral was not made. (Note: The program may include a traditional CR program based on face-to-face interactions and training sessions or may include other options such as home-based approaches. If alternative CR approaches are used, they should be designed to meet appropriate safety standards.) A referral is defined as an official communication between the healthcare provider and the patient to recommend and carry out a referral order to an early outpatient CR program. This includes the provision of all necessary information to the patient that will allow the patient to enroll in an early outpatient CR program. This also includes a written or electronic communication between the healthcare provider or healthcare system and the cardiac rehabilitation program that includes the patient's enrollment information for the program. A hospital discharge summary or office note may potentially be formatted to include the necessary patient information to communicate to the CR program (e.g., the patient's cardiovascular history, testing, and treatments). All communications must maintain appropriate confidentiality as outlined by the 1996 Health Insurance Portability and Accountability Act (HIPAA). *Exclusion criteria:* • Patient factors (e.g., patient to be discharged to a nursing care facility for long-term care). • Medical factors (e.g., patient deemed by provider to have a medically unstable, life-threatening condition). • Health care system factors (e.g., no cardiac rehabilitation program available within 60 minutes of travel time from the patient's home).
Denominator	Number of hospitalized patients in the reporting period hospitalized with a qualifying event/diagnosis who do not meet any of the exclusion criteria mentioned in the Numerator section. (Note: Patients with a qualifying event who are to be discharged for a short-term stay in an inpatient medical rehabilitation facility are still expected to be referred to an outpatient cardiac rehabilitation program by the in-patient team during the index hospitalization. This referral should be reinforced by the care team at the medical rehabilitation facility.)
Period of Assessment	Inpatient hospitalization.
Method of Reporting	Proportion of healthcare system's patients with a qualifying event/diagnosis who had documentation of their referral to an outpatient CR program.
Sources of Data	Administrative data and/or medical records.

Rationale

A key component to outpatient CR program utilization is the appropriate and timely referral of patients. Generally, the most important time for this referral to take place is while the patient is hospitalized for a qualifying event/diagnosis (MI, CSA, CABG, PCI, cardiac valve surgery, or cardiac transplantation).

This performance measure has been developed to help healthcare systems implement effective steps in their systems of care that will optimize the appropriate referral of a patient to an outpatient CR program.

This measure is designed to serve as a stand-alone measure or, preferably, to be included within other performance measurement sets that involve disease states or other conditions for which CR services have been found to be appropriate and beneficial (e.g., following MI, CABG surgery). This performance measure is provided in a format that is meant to allow easy and flexible inclusion into such performance measurement sets.

Effective referral of appropriate inpatients to an outpatient CR program is the responsibility of the healthcare team within a healthcare system that is primarily responsible for providing cardiovascular care to the patient during the hospitalization.

Corresponding Guidelines and Clinical Recommendations

ACC/AHA 2004 Guideline Update for Coronary Artery Bypass Graft Surgery (12).
Class I
Cardiac rehabilitation should be offered to all eligible patients after CABG (*Level of Evidence: B*).

ACC/AHA 2007 Update of the Guidelines for the Management of Patients With ST-Elevation Myocardial Infarction (13).
Class I
Advising medically supervised programs (cardiac rehabilitation) for high-risk patients (e.g., recent acute coronary syndrome or revascularization, heart failure) is recommended (*Level of Evidence: B*).

ACC/AHA 2007 Guidelines for the Management of Patients With Unstable Angina and Non–ST-Segment Elevation Myocardial Infarction (14).
Class I
Cardiac rehabilitation/secondary prevention programs are recommended for patients with unstable angina/non–ST-segment elevation MI, particularly those with multiple modifiable risk factors and/or those moderate- to high-risk patients in whom supervised exercise training is particularly warranted (*Level of Evidence: B*).
Cardiac rehabilitation/secondary prevention programs, when available, are recommended for patients with unstable angina/non–ST-segment elevation MI, particularly those with multiple modifiable risk factors and those moderate- to high-risk patients in whom supervised or monitored exercise training is warranted (*Level of Evidence: B*).

ACC/AHA 2007 Chronic Angina Focused Update of the Guidelines for the Management of Patients With Chronic Stable Angina (15).
Class I
Medically supervised programs (cardiac rehabilitation) are recommended for at-risk patients (e.g., recent acute coronary syndrome or revascularization, heart failure) (*Level of Evidence: B*).

ACC/AHA Guidelines for the Evaluation and Management of Chronic Heart Failure in the Adult (16).
Class I
Exercise training is beneficial as an adjunctive approach to improve clinical status in ambulatory patients with current or prior symptoms of heart failure and reduced left ventricular ejection fraction (LVEF) (*Level of Evidence: B*).

AHA Evidence-Based Guidelines for Cardiovascular Disease Prevention in Women: 2007 Update (17).
Class I
A comprehensive risk-reduction regimen, such as cardiovascular or stroke rehabilitation or a physician-guided home- or community-based exercise training program, should be recommended to women with a recent acute coronary syndrome or coronary intervention, new-onset or chronic angina, recent cerebrovascular event, peripheral arterial disease (*Level of Evidence: A*), or current/prior symptoms of heart failure and an LVEF $<$40% (*Level of Evidence: B*).

ACC/AHA/SCAI 2007 Focused Update of the Guidelines for Percutaneous Coronary Intervention (18).
Class I
Advising medically supervised programs (cardiac rehabilitation) for high-risk patients (e.g., recent acute coronary syndrome or revascularization, heart failure) is recommended (*Level of Evidence: B*).

Challenges to Implementation

Identification of all eligible patients in an inpatient setting will require that a timely, accurate, and effective system be in place. Communication of referral information by the inpatient hospital service team to the outpatient CR program represents a potential challenge to the implementation of this performance measure. However, this task is generally performed by an inpatient cardiovascular care team member, such as an inpatient CR team member or a hospital discharge planning team member.

Measure # 54: Cardiac Rehabilitation Patient Referral from an Outpatient Setting

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Performance Measure A-2

A-2. Cardiac Rehabilitation Patient Referral From an Outpatient Setting

All patients evaluated in an outpatient setting who within the past 12 months have experienced an acute myocardial infarction (MI), coronary artery bypass graft (CABG) surgery, a percutaneous coronary intervention (PCI), cardiac valve surgery, or cardiac transplantation, or who have chronic stable angina (CSA) and have not already participated in an early outpatient cardiac rehabilitation/secondary prevention (CR) program for the qualifying event/diagnosis are to be referred to such a program.

Numerator	Number of patients in an outpatient clinical practice who have had a qualifying event/diagnosis during the previous 12 months, who have been referred to an outpatient CR program. (Note: The program may include a traditional CR program based on face-to-face interactions and training sessions or other options that include home-based approaches. If alternative CR approaches are used, they should be designed to meet appropriate safety standards.) A referral is defined as an official communication between the healthcare provider and the patient to recommend and carry out a referral order to an outpatient CR program. This includes the provision of all necessary information to the patient that will allow the patient to enroll in an outpatient CR program. This also includes a written or electronic communication between the healthcare provider or healthcare system and the cardiac rehabilitation program that includes the patient's enrollment information for the program. A hospital discharge summary or office note may potentially be formatted to include the necessary patient information to communicate to the CR program (e.g., the patient's cardiovascular history, testing, and treatments). According to standards of practice for cardiac rehabilitation programs, care coordination communications are sent to the referring provider, including any issues regarding treatment changes, adverse treatment responses, or new nonemergency condition (new symptoms, patient care questions, etc.) that need attention by the referring provider. These communications also include a progress report once the patient has completed the program. All communications must maintain an appropriate level of confidentiality as outlined by the 1996 Health Insurance Portability and Accountability Act (HIPAA). *Exclusion criteria:* • Patient factors (e.g., patient resides in a long-term nursing care facility). • Medical factors (e.g., patient deemed by provider to have a medically unstable, life-threatening condition). • Health care system factors (e.g., no cardiac rehabilitation program available within 60 min of travel time from the patient's home).
Denominator	Number of patients in an outpatient clinical practice who have had a qualifying event/diagnosis during the previous 12 months and who do not meet any of the exclusion criteria mentioned in the Numerator section, and who have not participated in an outpatient cardiac rehabilitation program since the qualifying event/diagnosis.
Period of Assessment	Twelve months following a qualifying event/diagnosis.
Method of Reporting	Proportion of patients in an outpatient practice who have had a qualifying event/diagnosis during the past 12 months and have been referred to a CR program.
Sources of Data	Administrative data and/or medical records.
Attribution/Aggregation	This measure should be reported by the clinician who provides the primary cardiovascular-related care for the patient. In general, this would be the patient's cardiologist, but in some cases it might be a family physician, internist, nurse practitioner, or other health-care provider. The level of "aggregation" (clinician versus practice) will depend upon the availability of adequate sample sizes to provide stable estimates of performance.

Rationale

Cardiac rehabilitation services have been shown to help reduce morbidity and mortality in persons who have experienced a recent coronary artery disease event, but these services are used in less than 30% of eligible patients (19). A key component to CR utilization is the appropriate and timely referral of patients to an outpatient CR program. While referral takes place generally while the patient is hospitalized for a qualifying event (MI, CSA, CABG, PCI, cardiac valve surgery, or heart transplantation), there are many instances in which a patient can and should be referred from an outpatient clinical practice setting (e.g., when a patient does not receive such a referral while in the hospital, or when the patient fails to follow through with the referral for whatever reason).

This performance measure has been developed to help healthcare systems implement effective steps in their systems of care that will optimize the appropriate referral of a patient to an outpatient CR program.

This measure is designed to serve as a stand-alone measure or, preferably, to be included within other performance measurement sets that involve disease states or other conditions for which CR services have been found to be appropriate and beneficial (e.g., following MI, CABG surgery). This performance measure is provided in a format that is meant to allow easy and flexible inclusion into such performance measurement sets.

Referral of appropriate outpatients to a CR program is the responsibility of the healthcare provider within a healthcare system that is providing the primary cardiovascular care to the patient in the outpatient setting.

Corresponding Guidelines and Clinical Recommendations

See Clinical Recommendations section from Performance Measure A-1.

Challenges to Implementation

Identification all eligible patients in an outpatient clinical practice will require that a timely, accurate, and effective system be in place. Communication of referral information by the outpatient clinical practice team to the outpatient CR program represents a potential challenge to the implementation of this performance measure.

Measure # 55: Patients with a Transient Ischemic Event ER Visit that had a Follow Up Office Visit

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- Contact information unavailable.

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Measure # 56: Biopsy Follow Up

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Biopsy Follow Up Process Measure

American Academy of Dermatology

Measure Description: Percentage of patients who are undergoing a biopsy whose biopsy results have been reviewed by the biopsying physician and communicated to the primary care physician and the patient.

Numerator: Patients who are undergoing a biopsy whose biopsy results have been reviewed by the biopsying physician and communicated to the primary care physician and the patient, denoted by entering said physician's initials into a log, as well as by documentation in the patient's medical record.

Time Window: Measurement year.

Denominator: All patients undergoing a biopsy.

Time Window: Measurement year.

Exclusion: All patients not undergoing a biopsy.

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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Melanoma Continuity of Care – Recall System Process Measure

American Academy of Dermatology

Measure Description: Percentage of patients with a current diagnosis of melanoma or a history of melanoma who were entered into a recall system with the date for the next complete physical skin exam specified, at least once within the 12 month reporting period.

Numerator: Percentage of patients with a current diagnosis of melanoma or a history of melanoma who were entered into a recall system with the date for the next complete physical skin exam specified, at least once within the 12 month reporting period.

- A target date for the next complete physical skin exam, AND
- A process to follow up with patients who either did not make an appointment within the specified timeframe or who missed a scheduled appointment

*To satisfy this measure, the recall system must be linked to a process to notify patients when their next physical exam is due and to follow up with patients who either did not make an appointment within the specified timeframe or who missed a scheduled appointment and must include the following elements at a minimum: patient identifier, patient contact information, cancer diagnosis(es), dates(s) of initial cancer diagnosis (if known), and the target date for the next complete physical exam.

Denominator: All patients with a current diagnosis of melanoma or a history of melanoma.

Exclusion: Documentation of system reason(s) for not entering patients into a recall system (e.g., melanoma being monitored by another provider).

Measure # 62: Team Survey for Program of All-Inclusive Care for the Elderly (PACE)

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Measure # 63: Medication Reconciliation for Ambulatory Care

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Measure # 64: Promoting Health Development Survey PLUS (PHDS-PLUS)

Contact Information:

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