

Patients' Perspectives of Care Management: A Qualitative Study

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Risk-stratified care management is a cornerstone of the patient-centered medical home (PCMH) model, but studies on patients' perspectives of care management are scarce. PCMHs are intended to focus on patients' needs, so knowing patients' perspectives about care management is critical. To help bridge this gap in the literature, we conducted semi-structured interviews with patients or their caregivers in practices participating in a large initiative to understand their experiences with care management, what they found most useful, and what might be improved.

Care management is a "set of activities designed to assist patients and their support systems in managing medical conditions and related psychosocial problems more effectively."¹ It is also associated with a lower risk of complications.^{2,3} A common care management model in primary care includes the use of "care managers," a term we use to refer to the person who works with high-risk patients and primary care teams to develop care plans, improve patients' understanding and self-management of their chronic conditions, monitor chronic conditions between visits, and follow up after transitions in care, such as a discharge from a hospital or an emergency department (ED).^{1,4} Care managers are considered most effective when they work within a primary care practice, meet patients in person, communicate with them by phone between visits, and coordinate with their primary care physician.^{1,5} Care management can be provided by a care manager embedded within or external to the practice who works closely with the primary care clinician or by a primary care physician with the help of a medical assistant or other staff.^{1,4}

Through the Comprehensive Primary Care (CPC) initiative, CMS collaborated with 39 private and public payers to test care management, alongside other interventions, in nearly 500 primary care practices in 7 US regions. CPC ran from October 2012 through December 2016. Designed to reduce costs and improve primary care delivery, patients' and providers' experiences, and health outcomes, CPC gave participating practices non-visit-based payments and the opportunity to share in cost savings, regular feedback on patient

ABSTRACT

OBJECTIVES: Risk-stratified care management is a cornerstone of patient-centered medical home models, but studies on patients' perspectives of care management are scarce. We explored patients' experiences with care management, what they found useful, and what needs improvement.

STUDY DESIGN: Semi-structured qualitative telephone interviews.

METHODS: We interviewed 43 high-risk patients or their caregivers who were receiving care management from 11 practices in CMS' Comprehensive Primary Care initiative, provided by nurse care managers (9 practices) or the physician (2 [solo] practices).

RESULTS: Patients' perceptions of care management were mixed. Patients who had regular contact with, and a desire to work with, their care manager valued the care management services provided. These patients valued care managers who listened to them and explained their conditions and options in lay terms, helped them navigate the healthcare system and community resources, and followed up after hospitalizations. However, one-fifth of the patients in practices that used nurse care managers could not identify their care manager although we: 1) sampled patients who had recent contact with their care manager and 2) defined the care manager's roles and provided examples of typical care management activities. Patients' interactions with care managers from health plans and hospitals contributed to confusion.

CONCLUSIONS: Practices can improve patient buy-in for care management through in-person introductions to care managers by their physicians, offering care management to patients who need and are interested in it, broader agreement about terminology and the role of care managers and care plans, and better coordination with care management from insurers and hospitals.

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outcomes, and a learning network.⁶ The CPC initiative emphasized patient and caregiver engagement, and CMS held a number of technical advisory panels, which included patients, when they designed the initiative.

CPC required participating practices to risk-stratify patients and provide care management to those at highest risk by: 1) linking each active patient to a provider or care team, 2) defining each patient's level of need, and 3) managing each high-risk patient's care according to their needs.

Most CPC practices used embedded nurse care managers, either newly hired or trained "on the job" to provide care management. A few of these had been certified in case management.⁷⁻⁹ In some small physician-owned practices, the primary care physician performed the care management tasks, often with the help of a medical assistant.

Most literature on care management focuses on provider or delivery system, rather than patient, perspectives.¹ Two studies from Canada and the United Kingdom examined the patient's perspective of care management models and found that patients receiving care management perceived their care, psychosocial support, access to services, advocacy, and communication with providers favorably.¹⁰⁻¹² These studies called for more studies on patient perspectives on care management.

METHODS

Recruitment

As part of the CPC evaluation, we collected qualitative data annually from 21 CPC "deep-dive" practices (3 from each of the 7 CPC regions) about CPC implementation. We selected these deep-dive practices because they had characteristics similar to those of all CPC practices. Building on our relationships with these practices, we asked 11 of them ranging in size, ownership, and location to recruit high-risk patients for semi-structured interviews about care management. We interviewed patients in the middle of the third year of the 4-year initiative.

We gave a script and responses to frequently asked questions to care managers at the 11 practices who described the study to patients (or their caregivers) with whom they had contact over the next 2 weeks and asked if each would participate in 1 telephone interview. Each care manager compiled a list of patients who consented, their contact information, and whether they were discharged from a hospital in the previous month. The combined lists included 159 patients, all of whom were mailed an advance letter.

We explained to patients that their participation in the study was voluntary and would not affect their insurance coverage or

TAKEAWAY POINTS

Risk-stratified care management is a cornerstone of patient-centered medical home models, but studies on patients' perspectives of care management are scarce. We explored patients' experiences with care management, what they found useful, and what needs improvement.

- ▶ Patients who had regular contact with, and a desire to work with, their care manager valued the care management services provided. Patients valued having a care manager who listened to them and explained their conditions in lay terms, helped them navigate community resources, and followed up after hospitalizations.
- ▶ One-fifth of the patients in practices that used nurse care managers could not identify their care manager.
- ▶ Practices can improve patient buy-in for care management through in-person introductions to care managers by physicians, offering care management to patients who need and are interested in it, broader agreement about terminology and the role of care managers and care plans, and better coordination with care management from insurers and hospitals.

healthcare and that comments would not be shared with their primary care practice. Patients were offered \$25 to complete the interview.

Because our research examined a public benefit, the New England Institutional Review Board (NEIRB# 13-174) exempted the study. Respondents provided verbal consent first to their care manager to be included on the list of volunteers and again to the interviewer to participate in this 1-time interview.

Interviews

We conducted semi-structured telephone interviews from March to May 2015, starting with the first patient on each list and continuing until we completed 7 interviews per CPC region. Of the 159 patients, we attempted calls to the 138 for whom we had working phone numbers. These patients were distributed across regions. Forty-two patients did not answer the phone or return voicemails, 38 refused to be interviewed, and 15 had hearing, health, or time issues that made it difficult to interview them. There were no differences in mean age or disability status between responders and nonresponders, but responders were slightly more likely to be female (74% vs 63%). We completed 43 interviews (18 with patients who had recently been hospitalized). After completing 40 interviews, we received no new information, and all responses fit into the existing codes. The respondents were fairly evenly distributed across regions and practices per region (**Table 1**). A service transcribed the interviews verbatim.

Interview Topics

We based the interview protocol (see **eAppendix** [eAppendices available at ajmc.com]) on Bodenheimer's conceptual framework on care management,¹ the Chronic Care Model,^{13,14} and CPC requirements.⁶ We pilot tested and refined the protocol with CPC patients receiving care management.

We first asked about the patients' general experience with their primary care practice to see if patients in practices with nurse care managers mentioned the care manager without prompting. We then asked about these topics: 1) care management—how the

TABLE 1. Characteristics of Patient Respondents and Their Primary Care Practices

	Number of Patients	Number of Practices
Total patients and practices	43	11
Patient Characteristics^a		
Age, years		N/A
<65 (disabled)	15	
65-74	13	
75-84	10	
≥85	5	
Female	31	N/A
Patient had a hospital discharge in the month before the practice supplied his or her name to us	18	N/A
Practice Characteristics (at baseline)		
Practice size (number of clinicians at the site)		
1-2	7	3
3-5	17	4
6-10	12	3
≥11	7	1
Practice ownership		
Physician-owned	11	4
Hospital- or health system-owned	31	6
Other	1	1
Region		
Arkansas	6	2
Colorado	6	2
New Jersey	6	2
New York	4	1
Ohio/Kentucky	7	1
Oklahoma	7	2
Oregon	7	1
Care manager staffing ^b		
Full-time	27	6
Part-time	10	3
Physician as only care manager	6	2

N/A indicates not applicable.

^aAll patients interviewed were determined to be high risk by their Comprehensive Primary Care (CPC) practice's risk stratification and were receiving care management from their CPC practice when they were interviewed.

^bIn the 9 practices that had a care manager, their backgrounds, listed from most to least common, were registered nurse, licensed practical nurse, nurse practitioner, and advanced practice registered nurse. In some practices, care managers were aided by medical assistants. In 2 solo practices, the physician was the sole care manager, with help from a medical assistant or other staff.

practice introduced patients to its care manager, frequency of communication with the care manager, and kinds of support the care manager provided; 2) care planning and patient engagement—patients' understanding of and level of involvement in developing a care plan; the practices' understanding and incorporation of patients' needs, values, and goals for care into the plan; 3) care coordination—the practice's referral procedures for specialists, how the physician or care manager communicated with specialists, and whether the physician and/or care manager discussed the specialist's recommendations with the patient; and 4) care transitions—patients discharged from a hospital or an ED in the previous month were asked about their practices' follow-up.

Coding and Analysis

Using the aforementioned conceptual framework, we developed a coding rubric and dictionary¹⁵ to capture key themes.^{1,6,13,14,16} During the first weeks of data collection, the interviewers met weekly to discuss emerging themes, refine the coding rubric, and assess inter-rater agreement on a set of transcripts coded simultaneously. Two interviewers coded the transcripts using the qualitative analysis software NVivo10 (QSR International; Burlington, Massachusetts). We built frequent debriefings and peer review by the research team into the coding and analysis to maximize the reliability of coding and to reduce researcher bias.^{17,18}

RESULTS

Practice and Patient Characteristics

Based on data they reported to CMS, 6 of the 11 practices we studied had a full-time nurse care manager and 3 had a part-time nurse care manager. In the 2 solo practices, the physician, helped by a medical assistant or other staff, was the sole care manager. This distribution of staff was, according to data that practices report to CMS annually, similar to the 2015 distribution of care manager staffing across all CPC practices.

Thirty-seven of the 43 respondents who completed interviews were patients and 6 were caregivers who responded for patients who lacked the cognitive or physical ability to respond for themselves (Table 1). Thirty-one of the 43 were in system-owned practices, 28 were 65 years or older, and 15 had disabilities. Eighteen patients were discharged from a hospital in the previous month.

About half the patients were with the same practice for 10 or more years (ranging from 6 months to 32 years). More than half reported visiting their practices 2 to 6 times per year; 10 reported visiting at least monthly.

Patients' Perceptions of the Care Team

When asked about the composition of their primary care team, patients typically identified their physician and the nurse or

medical assistant with whom the physician worked most closely during their routine, comprehensive, and acute care visits. All interviewees reported that their lead clinician was a physician. Most patients who said that they had a care manager felt that the care manager was an important part of their primary care team.

In many of the practices that had a nurse care manager, the primary care physician or another person in the office introduced the patient to the care manager during an office visit. Echoing the experience of others, a patient said, "She came in [during my visit with my physician] and introduced herself and told me if I had any problems I should call her...She gave me her card...[and] then she would call every couple days and make sure that my blood pressure's down, and she coordinated with [my physician]." A few patients first met their care manager after a hospitalization, through a phone call from the care manager or during a visit by the care manager in the hospital.

One-fifth of patients were not familiar with the concept of a care manager and had trouble identifying who played this role although we intentionally sampled patients who had recent contact with their care manager and interviewers defined a care manager's role for the patients, including examples of what that person typically does. (This proportion does not include the patients in the 2 solo practices whose physicians performed care management tasks.)

Outreach from CPC practice care managers, health plans, and hospitals to patients at the time of hospital discharge contributed to patient confusion about the role each person played in their care and about who their care manager was. This duplicate outreach was an issue for approximately one-third of the patients with a hospitalization in the previous month. One patient who was confused about the identity of his care manager noted, "To be truthful, my Medicare supplements [supplementary insurance plan] has tried to take on the role of a care manager."

A few patients preferred not to interact with a care manager, particularly older patients who had a longstanding relationship with their primary care physician. One, for example, preferred to rely on her primary care physician of 20 years: "[He] is the one I can talk to the easiest. I am a firm believer in primary care doctors because I totally think that they are the ones who know a patient the best."

Development of Care Plans

CPC guidance to practices¹⁹ notes that an essential feature of care management is "a mutually agreed upon and documented plan of care, based on the patient's goals and the best available medical evidence; it is accessible to all team members...and addresses all major and significant ongoing health problems and risks." Although the initiative did not require practices to give patients a copy of their care plan, the patient's involvement in goal setting was implicit in the CPC definition of a care plan. Few patients, however, had heard the terms "plan of care" or "care plan," and many did not understand this concept even after we described it. After probing by

TABLE 2. Patient Reports of Responses by Care Managers

- Taught patients about their conditions and how to manage them
- Tracked patients' chronic condition management over time
- Followed up with patients after an emergency department visit or hospital discharge
- Monitored medications
- Facilitated communication between the patients and the primary care physicians*
- Helped patients get access to community support services (eg, exercise programs)
- Provided emotional support
- Navigated the healthcare system and community-based supports

*In practices that used a nurse care manager.

the interviewers, about a quarter of the patients described formal care plans and goals (including steps for achieving them), which they had set with their physician and/or care manager.

Patients varied widely in the degree to which they wanted to contribute to their care plan. About one-third of respondents mentioned that they were too old or sick to consider their goals or to develop such a plan and preferred to rely on their doctors' opinion. Another one-fourth of respondents reported being very engaged in their care planning; of these, a handful had only recently become more engaged in their healthcare either because of failing health or their physician's or care manager's encouragement. The remainder of respondents did not understand the concept of care plans after we described it and thus could not comment on the extent to which they would want to contribute.

Only 1 patient reported having a copy of her care plan. Patients typically described a discussion or a verbal agreement with their primary care physician: "He didn't write all that down. We just had a good discussion about my age, getting older, and stuff like that, and what I need to be aware of and start doing to help stay healthy." For patients who could not articulate their goals and did not recall discussing them with their primary care physician or care manager, it is unclear whether someone in their practice created a care plan for them but did not share it or whether a plan was not created.

Care Management Activities

Care managers communicated with patients primarily by phone and during office visits; a few used e-mail or text messaging. Patients who reported regular contact with a care manager said that they primarily received follow-up after hospitalizations, help with the ongoing management of chronic conditions, medication monitoring, navigating the health system and community services, and other forms of assistance (Table 2). These activities are consistent with those required by CPC.

Several care managers helped patients and caregivers navigate the healthcare system and community-based resources when they needed medical equipment, home health care, or affordable

medications. As one patient noted, “[The care manager] was a go-between with the [staff at the Agency] on Aging, who were case managing my home modification, and between some of the providers, and then also [for] anything that we needed from [my primary care physician], like a prescription for grab bars or a wheelchair.”

Care managers also helped patients and caregivers prepare for being discharged from hospitals and EDs. A spouse caregiver noted, “[The care manager] helped us go through some of the parameters of what would be a good [rehabilitation program] for him. Then she just kept in touch with us about things that we might need [and] resources in the community...so that [my husband] could come home rather than have to go to a nursing home indefinitely.”

Patients in most practices reported that their care manager played less of a role in coordinating with specialists. In general, clerical staff in the practices helped patients make appointments with specialists and tracked down the specialists’ notes; physicians then explained the specialists’ recommendations to patients.

Patient Satisfaction With Care Managers

Over half of patients reported having regular contact with their care manager and were willing to work with their care manager to manage their health conditions; such patients felt that the care manager was an asset to their team. In addition, there were patients who needed less frequent contact, but still valued help from care managers.

Many patients valued their care manager’s help in managing and monitoring their chronic conditions. As one patient reported, “[My care manager] calls on a regular basis to check in on me and see...if I need anything or basically how I’m feeling and if I think [my physical therapy] is helping me.” Some of these patients noted that their care manager offered them practical advice on how to meet their health goals. One said, “They know that it’s hard for me to exercise—but they still encourage me to do what I can. [My care manager] told me to take 2 cans of soup and put ‘em on the top of my feet and just raise ‘em up..., but that’s a suggestion that I wouldn’t have thought of.” They appreciated that their care manager took the time to help them understand how to implement their physicians’ recommendations and how to stay well after a hospitalization.

Patients were also pleased with their care manager’s assistance with managing medications. One patient said that his care manager was particularly valuable when his medications were adjusted: “When we add one [medication], or we change one, it changes everything else. Because I take so many, it’s a complicated thing.”

DISCUSSION

Patients who reported having regular contact with their care manager or who were open to working with their care manager felt that the care manager was an asset to their team. Patients particularly valued care managers who listened to them and explained things in

lay terms, helped to manage medications and chronic conditions, followed up after a hospitalization, and helped to navigate the healthcare delivery system and community resources.

Although we purposely selected patients who were, according to their primary care practices, receiving care management services, one-fifth of patients (or their caregivers) could not identify a person at the practice other than the physician whom they felt fit the role of a care manager as we described it to them. This may reflect several factors, including inadequate integration of nurse care managers into primary care teams, lack of patient interest in engaging with a care manager, and repeated interactions with many individuals, such as home health aides and care managers from insurers and hospitals. We found variation among deep-dive practice clinicians’ efforts to introduce care managers to patients in person.⁸ Others have noted challenges to integration of care managers into the practice team, including a lack of experience with and knowledge of the best ways to design and implement effective care management; the limited availability of high-quality, standardized training for care managers; and a need to train practices to collaborate effectively with care managers.²⁰ Other patients preferred not to interact with a care manager.

It is likely that most patients barely recognized the term “care plan” because practices did not develop the plans systematically. Based on our site visits to the deep-dive practices,⁸ there is variation in the extent to which care plans are developed, used by care team members in a practice, and shared with patients.

Given that we interviewed selected patients in selected practices in 1 initiative, our findings cannot be generalized to all CPC practices or all patients receiving care management. In addition, CPC practices received funding and learning support for care management, and other practices—particularly small, independent, or rural ones—may not have the financial resources or enough local nurses to hire even part-time care managers.²¹

Nonetheless, the patient and caregiver feedback identifies ways primary care practices can improve care management: 1) Enhance the initial connection between patients and care managers by having physicians introduce care managers to patients in person and describing the benefits of care management; 2) Consider testing whether risk-stratification could also identify patients who might be amenable to changing health behaviors. Some patients who reported having limited contact with their care manager did not feel that they needed care management. Refining risk-stratification to identify patients willing to engage with care managers could focus care management resources on patients who need and are willing to use the services; 3) Train care managers to engage patients. Care managers, particularly those who lack formal case management training, may need guidance on gaining buy-in from disinterested patients. Because a few patients reported that their care manager did not initiate regular communication but advised them to call with questions or concerns, a more proactive approach may be beneficial; 4) Provide clinicians with technical assistance on how to explain the

care manager's role and how to delegate aspects of care to care managers in a way that is congruent with each care manager's training, experience, licensure, and skills; 5) Coordinate care management resources across providers and health plans. Given the confusion among patients who also received outreach from "care managers" from health plans and hospitals, better coordination across these entities is necessary^{22,23}; 6) Improve the use and understanding of care plans among clinicians and patients. Practices may need to better engage willing patients in care plan development to make the plans more recognizable and useful to patients; and 7) Use consistent terminology for "care manager" and "care plan" and develop broader agreement on the elements of these plans. This might help to promote a common understanding among providers and patients about care management and solidify provider and patient buy-in. Standardized terminology might also enhance efforts to evaluate patients' experience with care management.

CONCLUSIONS

Patients who reported regular contact with their care manager or a willingness to engage in care management noted its numerous benefits, but challenges to engaging patients in care management remain. Future research on their experiences with care management might include how researchers and practices could best gather patient feedback, particularly when patients' frailty or lack of time make this challenging. Research on the best language to use with patients and providers to refer to care management and care plans and effective ways to gain and maintain patient buy-in would also be helpful.

Ongoing assessment of patients' experiences and engagement with care management is essential. As active partners in care management, patients' feedback can help inform both internal practice processes as well as how care managers, clinicians, and staff engage with patients. ■

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eAppendix. Care Management Semi-Structured Interview Protocol

Introduction

Today we'd like to discuss with you the care you get from your **primary care doctor's office**.¹

This interview is sponsored by the Centers for Medicare & Medicaid Services (CMS) and is being conducted by separate organizations called Insight and Mathematica Policy Research. This interview is for a program your practice is participating in to try to improve medical care.

Your privacy is protected. All information that would let someone identify you or your family will be kept private. We will **not** share your personal information or responses to the interview today with anyone. The doctor's office we ask about will not know your individual responses. Your responses are completely confidential.

Your participation is voluntary. You may choose to speak with me today or not. If you choose not to, this will not affect the health care you get or your insurance coverage. The interview should take about 45 minutes. To thank you for your time, we will send you a check for \$25 as a token of our appreciation.

We'd like to tape this interview so that we can refer back to it for our analysis. Is that all right?

Do you have any questions before we begin?

Warm-Up Questions

1. How long have you been a patient at your primary care doctor's office?
2. About how often do you make a visit to this doctor's office?
3. Who is your primary care doctor?

4. Are there other people on the team at this practice that care for you?

PROBE for each person they mention: What kinds of things does this person do for you?

5. There are many ways that patients and doctors can work together to manage a person's health care. For example, some patients rely completely on their doctor to know what is best for them, while others like to take a more active role in the decisions that affect them. Would you say you take more of an active role or rely more on your doctor?

PROBE: Do you ask questions and share your views about what you think is best for you, or do you prefer to rely on your doctor's opinion?

¹ Since none of the deep-dive practices were led by nurse practitioners, we used a term most patients typically use: "your doctor's office."

6. Who at your doctor's office talks to you about your condition or treatment options? *[Probe them to list each person at the practice that discusses treatment options]*
 - a. *[PROBE for each person listed]:* Do they talk to you about your condition in a way that is easy for you to understand?
 - b. *[PROBE If respondent says hard to understand, ask:]* How could they make it easier for you to understand?
 - c. *PROBE:* Who at the practice do you find easiest to understand? Tell me more about this.

General Questions about Doctor/Care Manager and Practice Team Involvement in Care

Care Planning and Patient Engagement

7. A **plan of care (or care plan)** is an agreement about how you and your health care providers are going to manage your health conditions. Have you and your primary care providers discussed a **plan of care**?

PROBE: If respondent doesn't recognize the term ask:

Do you have a care plan or description of your health care goals? (This usually includes identifying your health goals and how you are going to achieve them. It includes information on managing your conditions and medications.)

[If the respondent doesn't seem familiar with the term "plan of care" or "care plan," please note that and skip Q8, and go to the next section on CARE MANAGEMENT]

8. At some practices, both the doctor and another person, like a nurse, work with the patient to (develop a plan of care) to help you manage your health problems.

- a. Who at the practice helped you develop this plan of care?

PROBE: Was this just one person or was more than one person involved?

- b. Has someone from the doctor's office (or "this person," if they are referring to someone in particular) given you a copy of your care plan?

- c. Is it a paper copy, or is it something you can view on the computer?

Care Management

The next few questions ask about how your primary care practice helps you to manage your care.

The term "care manager" is sometimes used to refer to the person from **the primary care practice (or who works with your primary care practice)** to check up with you on how you are doing. This contact with the care manager may occur during visits to your primary care doctor's office, or by phone or email between visits. Sometimes it also includes visits to your home. This person might help you learn about managing your health conditions, or may follow up with you after you are discharged from a hospital. In some practices, this person may be a nurse or social worker. In other practices, it might be the primary care doctor.

9. Who is your care manager? (Probe beyond the person's name to determine whether it's the doctor/nurse/ medical assistant or someone else).

If patient provides you with a name for their care manager: Cross check response with our list to see if it's the same name provided by the primary care practice's care manager. If not,

PROBE: Is [care manager name on MPR list] someone that helps with your care?

If given more than one name, ask: Of these people, who do you feel is more involved in helping you with your care over time?

[In remaining questions, refer to whichever of these two people the respondent says is more involved in their care.]

[If patient doesn't know the name of says they don't have a care manager]:

10. Thinking about the doctors, nurses and other staff in your primary care practice, who would you say is the person who seems to play this role of care manager?

PROBE: If you are not sure, let's talk about some of the different people from your practice that you might see or talk with, and what each person typically does with you or for you.

[Interviewer will determine from these responses which is the care manager based on which person from the practice interacts most with the patient and which seems to be the one helping the patient to manage their chronic conditions over time, not just during office visits, but also between visits, e.g., by phone]

- d. How were you introduced to _____? [Insert name/term patient used to refer to the care manager in response to Q10—Note: this may be a nurse, care manager, primary care physician, or medical assistant]
 - e. When did you begin working with [CARE MANAGER]?
 - f. How does the [CARE MANAGER] communicate with you? [PROBES: In-person at your provider's office? Over the phone? By email?]
 - i. How often do you talk with your [nurse] care manager?
 - g. What kinds of things does [NAME] help you with? (ASK FOR EXAMPLES)
 - i. If you take medication, does the [nurse] care manager help you understand your medication(s)? Please tell me about that.
 - ii. What were you told about when and how to contact your [care manager/nurse]?
 - h. How well does this person understand your needs? Tell me more about this.
 - i. Does s/he give you the opportunity to ask questions? Tell me more about this.
 - j. Does s/he ask you about your goals for your health and plan of care?
 - i. If so, how did s/he do that?
 - ii. What would you have liked him/her to have done differently (in addressing your goals)?
11. How involved would you say you are in making decisions about your health treatment plan?
12. How did s/he talk with you or your family about what to do if your symptoms worsen?

- 13. How well does the [CARE MANAGER] communicate with your primary care doctor about your care?
 - k. *PROBE:* Do they both seem to know what the other is doing for your care or not? Do they each let the other know when you need to see them or not?
 - l. *PROBE:* Do you consider the care manager a part of your primary care team?
- 14. What could your care manager do better to help you manage your health concerns?
- 15. What else could your doctor do better to help you manage your health concerns? *[If the doctor is the care manager, do not ask this question]*

Care Coordination

Next, we want to get your opinions about how your care is handled when you need to seek care from someone outside of your primary care doctor’s office. For example, sometimes patients may need to see a specialist like a surgeon or heart doctor or a home health provider.

- 16. Does your primary care practice play a role in getting you to see a specialist like this if you need one?
 - m. Can you walk me through the process by which you get referred to specialists?
 - iii. Who at the practice helped you with this?
 - iv. What do you like about this process?
 - v. What do you dislike about this process?
 - n. Can you remember the first time your practice helped you in this way?
 - PROBE:* Was it always that way or was this a recent change in the past couple of years?
 - o. Does your provider usually know the results of your visit with a specialist? *PROBE:* Do they refer to test or lab results or notes from the specialist during the next office visit?
 - p. What could the practice do better to help you understand the care you receive from specialists?

Care Transitions

- 17. Have you been to the hospital or the emergency department in the past six months? *[If yes, ask Q18–20; if no, skip this section and go to Q21]*
- 18. Which one did you have, an emergency room visit or a hospitalization? *[If they say they went to the emergency room first and then got hospitalized from the ED, use the hospital term below]*
- 19. Thinking about your **most recent** hospitalization/emergency department visit: Did someone at your primary care practice contact you to see how you were doing after your hospital stay/ED visit? If yes, ask:

- q. Who contacted you from the practice? (If they don't identify person's role, then Probe: care manager, nurse, front desk, medical assistant, doctor.)
 - r. How did they contact you?
 - vi. *PROBE:* By phone
 - vii. *PROBE:* by home visit
 - viii. *PROBE:* by email
 - s. What did they discuss with you during this contact?
 - t. Did they have you come in for an office visit?
 - u. What did they do that you found helpful?
20. Is there something your primary care doctor or his/her office could have helped you with after your hospital discharge/emergency department visit that they did **not** do?
- v. *PROBE:* Did you need help with your hospital discharge/ED instructions?
 - w. *PROBE:* Did you have questions about your medications?
 - x. *PROBE:* Did you have questions about conflicting advice from different doctors?

Changes at the Practice

21. Have you noticed any changes in how people at your doctor's office support you or communicate with you over the past year or two?

IF "YES" ASK: What changes have you noticed?

When did you first notice the change?

What do you think about these changes? [*PROBE:* What do you like about them?

What are some things that you don't like about them? Why?]

Thank you for taking the time to share your experiences with us today. This will help us to improve care for people like you.