

Medicare Health Care Quality (MHCQ) Demonstration Evaluation

Guide for RTI Staff Conducting Focus Groups with Caregivers of Medicare Beneficiaries Participating in the Gundersen Health System Advanced Disease Coordination Program

NOTE: This protocol will be used for focus groups with family caregivers or caregivers in the home who are not medical professionals.

A) Introduce RTI staff, provide background on roles of RTI and CMS in the MHCQ Demonstration Evaluation

Hello and thank you for agreeing to meet with us today. My name is [] and I work with RTI International, a nonprofit research organization. I would like to introduce [], who also represents RTI International.

We are working on a project funded by the Centers for Medicare and Medicaid Services (CMS) to learn about your family member's experiences in receiving services that are provided as part of the Advanced Disease Coordination (ADC) Program at Gundersen Health System (GHS), and your own experience with the ADC Program as well. Your experiences will help us understand how the ADC program works for both patients and their caregivers.

My role is to guide our discussion and to encourage everyone to share their experiences in the Gundersen ADC Program.

Before we get started, I'd like to go over a few things.

B) Review focus group process, ground rules for participation

First and foremost, during our discussion today, please keep in mind that there are no right or wrong views or answers. Everyone's opinion is important, so don't hesitate to speak up regardless of whether you agree with what has been said. In fact, if you have a different idea or feeling, we especially want to hear from you so we can better understand all the ways people think or feel about a subject.

To make sure that we understand everything you say today, we are making an audio and video recording of this discussion. We will also take notes. So we can hear everyone clearly, we ask that only one person speak at a time. Even if you disagree with what someone says, please allow that person to speak before you respond. It seems that every group has one or two "quiet" people, and if you are one of those, I might call on you! You are free to say that you'd rather "pass," but I'm hoping to hear from everyone at some point during our discussion.

Your participation in this focus group discussion is voluntary. You can choose not to answer any question or end your participation and leave the room at any time. We will not share any of your comments with your doctor, your insurance provider, or anyone else in such a way that you can be identified. We will not list your name in any written notes or

transcripts. We will make sure that information that you share with us today is kept and handled in a private and secure way. We will not put names in any reports. Our job is to ask questions and make sure we understand what you're saying. We also want to make sure that everyone has a chance to share their ideas.

Our discussion will last about two hours. I'll balance the amount of time we spend on each question, since we have a lot to get through. We won't be taking an official break, but if you need a personal break, please feel free to take one. [DESCRIBE LOCATION OF RESTROOMS AND REFRESHMENTS.]

- C) **Hand out the name badges and ask to write first name only.** [CAN BE FILLED OUT BY PARTICIPANTS AS THEY ARRIVE].
- D) **Review informed consent process, obtain the signature of each focus group participant on an informed consent form.** [CAN BE REVIEWED WITH PARTICIPANTS AS THEY ARRIVE OR JUST AS THEY ENTER THE ROOM, DEPENDING ON WHICH OPTION IS MORE PRACTICAL FOR THE PARTICULAR SET UP].

Do you have any questions about the consent form? If you are okay with this, please sign the informed consent form and pass it to us.

COLLECT INFORMED CONSENT FORMS; IF A PARTICIPANT IS NOT COMFORTABLE SIGNING THE FORM, HE/SHE CANNOT PARTICIPATE IN THE DISCUSSION.

E) **Introductions**

To begin, let's go around and introduce ourselves. Please tell us your first name and something you like to do for fun or a hobby that you have. I'll go first...

Beneficiary and Caregiver Experience with Care

The primary purpose of today's discussion is to learn about your experiences and the experiences of the person you care for with the ADC program at GHS. We will be discussing the care he/she receives through this program.

I want to discuss one other important issue before we get started. Many of us enjoy talking about our own health, or the health of the person you care for. However, the focus is **on experiences with the ADC staff and providers**, so please limit comments about the health or medical condition of the person you care for to facts that may have **affected** his/her experience. Please don't be offended if I ask you to clarify **how** his/her health or medical conditions shape his/her experience with providers or if I move discussion along to the next topic.

Do you have any questions?

[ANSWER ANY QUESTIONS.]

Good, let's get started!

F) Focus group discussion questions:

First, we would like to understand your role as a caregiver.

- 1) As a nonmedical caregiver in the home, how do you assist the person you care for? For example, what kinds of things do you do for him/her? [PROBES: Help them with their daily activities? Plan and prepare meals? Run errands?] How do you assist them with their health care needs? [PROBES: Make doctor appointments for them? Go with them to their doctor appointments? Remind them to take their medication? Help them with physical therapy? Monitor their health status by taking blood pressure, checking their blood glucose levels, or other things?]

Today's discussion is about the ADC program at GLHS. You might be familiar with this program from recent interactions with the providers that are part of the ADC team. The ADC team may include his/her primary care doctor, nurse care coordinator, palliative care provider, social worker, pastoral care provider, and other health care professionals. Are you all more or less familiar with the "ADC program?" [OBSERVE nods, if needed discuss how GLHS staff members are part of the ADC program.]

- 2) How did you learn about the ADC program? [PROBES: Did the primary care doctor or palliative care provider of the person you care for tell you about the program? Did the person you provide care for tell you about the program? Were you or the person you care for contacted by GLHS to participate in ADC?]
- 3) What helped the person or family member you care for to decide to participate in the ADC program? Who was involved in that decision? Was it a shared decision to be a part of the program? What were the top three things that mattered to him/her most in deciding to participate in this program? What were the top three things that mattered to **you** as a family member or non-medical caregiver?
- 4) As a non-medical caregiver in the home, do **you** interact with the ADC team either separately or together with the person you care for? [PROBES: participate in physician visits; consult the care coordinator; what else?]
- 5) Does the ADC team seem to understand the unique needs of the person or family member you care for? Do they consider his/her cultural beliefs and personal values when discussing his/her condition or treatment options? [PROBE: Do they understand challenges that he/she may have in making an appointment, his/her home situation, or other things that are important that may get in the way of his/her health care?]
 - a. What could the ADC program staff do to better understand the values, preferences for treatment, or unique needs of the person you care for?

- 6) There are many ways that patients and health care providers can work together to manage the patient's health or medical condition. For example, some patients always depend on their doctor to know what is best for them, while others take a more active role in the decisions that affect them. How much of a role does the person you care for take in his/her your own care? [PROBE: Does he/she ask questions, share views about what he/she thinks is best for him/her? Does the person you care for rely on you, his/her doctor, or someone else to remind him/her to see a specialist?] How often do the person you care for and the ADC team discuss different treatment options?
- 7) We now would like to ask some questions about the Next Steps Conversation. This conversation involves discussing and documenting the wishes of the person or family you care for. Did the person you care for participate in a Next Steps Conversation? Were **you** involved in that process? If so, please describe.
 - a. How did you and the person you care for learn about Next Steps? What questions did you have?
 - b. What things did **you** like about this process? What could be improved?
- 8) What was **your** experience with the Statement of Treatment Preferences? Were you involved in the development of that document?
 - a. What role did the person you care for play in developing these documents? What role did **you** play? How did the ADC team help the person you care for during the process? What things could be improved about the process of creating this document?
 - b. Is this document important to him/her? Why? Are they important to **you**? Why?
 - c. Who has copies of this document?
 - d. What things do you like about this document? What things could be improved about this document or about the process of creating it?
- 9) Another important document that the ADC team recommends every person has in place is a power of attorney for health care. This document appoints someone to make health care decisions for you. The ADC team may help patients to develop this document. Did the person you care for fill out a power of attorney for Health Care and give it to GLHS?
 - a. What role did the person you care for play in developing this document? What role did **you** play? How did the ADC team help the person you care for during the process? What things could be improved about the process of creating this document?
 - b. Why are these documents important to him/her? Why are they important to **you**? Who has copies of this document?
 - c. What things do **you** like about this document? What things could be improved about this document or about the process of creating it?
- 10) How does the ADC team help you or the person you care understand his/her condition or treatment options? Do they explain the pros and cons of different treatment options? Are they willing to answer questions?

- 11) What does the ADC team do to help you or the person you care for to take better care of himself/herself and his/her medical condition? [PROBES: Nurses review the medications he/she takes, screen for more conditions, discuss care planning, assess depression and anxiety, conduct patient and family conferences, etc.] Does the person you care for like or dislike how the ADC team does things? Do **you** like or dislike how they do things? Why?
- 12) How does the ADC team involve **you**, as a family member or non-medical caregiver, in the care plan for the person you care for? [PROBES: Do they ask **you** about how you could help to develop plan? Did they ask **you** if you understood the plan? Did they answer **your** questions about the plan? Do they ask you about updating or changing the plan?
- 13) Can you or the person you care for contact someone from the ADC team to answer questions or assist him/her when his/her doctor is not available?
 - a. Do they help the person you care for arrange to see his/her doctor when needed?
- 14) Has the ADC team or the primary care doctor of the person you care for invited you and/or the person you care for to suggest ways they could improve your experience?

Next, we want to talk about how the person you care for gets care from someone other than his/her primary care doctor. For example, sometimes the person you care for may need to see a specialist— like a palliative care provider for pain and symptom management, heart doctor, allergy doctor, psychiatrist, foot doctor, surgeon, or others who specialize in specific types of care.

- 15) What types of providers other than his/her primary care doctor does the person you care for see for other types of care? [Probe on each provider and types of interactions that they have with them.] What type of care did the person you care for receive from each of these providers (surgery, counseling, medication, x-ray, chemotherapy, etc.)?
 - a. How does the ADC team assist in getting the person you care for a referral or appointment to see a specialist? How does this arrangement work out for the person you care for? What does he/she like about it? What do **you** like or dislike about it?
 - b. Does the primary care provider of the person you care for know the results of his/her visit with a specialist? [PROBE: Do they talk about test or lab results or notes from the specialist?]
- 16) When the person you care for goes to his/her primary care doctor for a medical visit, how does the doctor know if the person you care for has visited the emergency room, been hospitalized, or had a nursing home or rehabilitation stay since his/her last office visit?
 - a. Does the ADC team know when the person you care for has visited the emergency room, been hospitalized, or had a nursing home or rehabilitation stay? How do you think they know?
 - b. How does the primary care provider know about new prescriptions or procedures that were done?

- c. How do you think they know?

17) Who from the ADC team assists the person you care for as he/she is admitted or discharged from the hospital?

- a. How did they help him/her?

We now would like to ask about experiences with different ADC team members, such as palliative care providers, nurse care coordinators, social workers, counselors, or chaplains and pastoral care counselors. These people may contact the person you care for by phone, by email, or through a home visit to help him/her with his/her care.

18) Has the person you care for worked with palliative care providers through the ADC program?

[If yes...]

- a. How did the person you care for first meet the palliative care providers? [PROBE: Did his/her doctor introduce them?] How did **you** first meet them?
- b. When did the palliative care providers start to work with the person you care for?
- c. How do the palliative care providers help the person you care for?
- d. How do the palliative care providers usually communicate with the person you care for? [Probe: In doctor's office, home visit, phonecall] Do they communicate with **you**?
- e. What does the person you care for like or not like about the palliative care providers? What do **you** like or not like about the palliative care providers?
- f. **Does the person you care for receive** care from palliative care providers outside of the ADC program?

19) Does the person you care for have nurse care coordinators in the ADC program that call him/her every so often, visit him/her at home, or that he/she can call when he/she has questions?

- a. How did the person you care for first meet these nurses? [PROBE: Did his/her doctor introduce them?] How did **you** first meet them?
- b. When did the nurses start to work with the person you care for?
- c. How do the nurses help the person you care for? [Probe: Have the nurses helped him/her manage his/her condition(s)? Have the nurses called the person you care for when he/she returned from the hospital? Have the nurses made visits to his/her home? Have the nurses helped him/her schedule an appointment with his/her primary care provider?]
- d. How useful are the nurses?
- e. How do the nurses communicate with the person you care for? [PROBES: In-person at your doctor's office? In-person at the home of the person you care for? Over the phone?] How often do they contact him/ her? Do they contact **you**? How often?

- f. If the person you care for takes medication, how do the nurses help him/her understand his/her medication? How useful is this to you or to the person you are taking care of?
- g. What does the person you care for like or not like about the nurses? What do **you** like or not like about the nurses?

20) Do you or the person you care for interact with a social worker?

[If yes...]

- a. How does the social worker help him/her?
- b. How does the social worker usually communicate with him/her? [Probe: In doctor's office, home visit, phone call] Do they communicate with **you**?
- c. What kinds of resources and support does the social worker discuss?
- d. What does the person you care for like or not like about the social worker? What do **you** like or not like about the social worker?

21) Has the person you care for worked with a pastoral care counselor or chaplain through the ADC program?

[If no...]

- a. Have you heard about such service? [If yes] What were some of the reasons that you were not interested to use this service?

[If yes...]

- b. How does the counselor/chaplain help him/her?
- c. How does the counselor/chaplain usually communicate with the person you care for? [Probe: Home visit, phone call, in the hospital] Do they communicate with **you**?
- d. What did the person you care for like or not like about the counselor/chaplain? What did you like or not like about the counselor/chaplain?

22) Has anyone from the ADC team (for example, a social worker or nurse care coordinator) told you or the person you care for about services available in the community? [PROBE: Such services may include Meals on Wheels, housing options, social activities at the local seniors' center]

- a. Does the person you care for receive services from any of these community resources?
- b. Has his/her primary care provider or someone else from the ADC team asked if he/she uses any of those community resources? Did they ask him/her about his/her experiences with these resources?

23) What kinds of support and resources does the ADC program provide to **caregivers** like you?

24) Overall, what are some of the things that **you** like about the ADC program? What are some of the things about the ADC program you do not like? Do you think the ADC program is beneficial? If so, why?

25) Would you recommend the ADC program to your friends? Why or why not?

26) If you could change or improve one thing about the ADC program, what would it be?

27) If the ADC program ended today, what would it mean for you?

These are all of our questions. Is there anything else you would like to share in regard to your regular care team that we haven't already discussed?

[Distribute honoraria and forms to sign for receipt of honoraria.]