

Medicare Health Care Quality (MHCQ) Demonstration Evaluation

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

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 experiences in receiving services that are provided as part of the Advanced Disease Coordination (ADC) Program at Gundersen Health System (GHS). Your experiences will help us understand how the ADC program works for 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 discussion is voluntary. You can choose not to answer any questions 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 collected data 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.

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 FOCUS GROUP.

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 Experience with Care

The primary purpose of today's discussion is to learn about the care that you receive from your primary care doctor and the ADC team members working with your doctor. The ADC team may include nurses, social workers, or chaplains. They may call you on the phone to check in or visit you at home. During the next two hours, I will be referring to these people as your "**ADC team.**" When answering questions, please think about the people on your ADC team and the services they provide.

Do you have any questions so far, especially about what we mean by your "ADC team?"

I want to discuss one other important issue before we get started. Many of us enjoy talking about our own health. However, the **focus is on your experience with primary care teams and providers**, so please limit comments about your health or medical condition to facts that may have **affected** your experience. Please don't be offended if I ask you to clarify how your health or medical conditions shape your experience with your 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:

Today's discussion is about the program called "Advanced Disease Coordination" (ADC) and your care team from that program. You might be familiar with this program from your recent interactions with your primary care doctor for the ADC team.

- 1) How did you learn about the ADC program? [PROBES: Did you receive a letter telling you about this program? What did the letter say?]
- 2) What helped you to decide to participate in the ADC program? Who was involved in that decision? What were the top three things that mattered to you most in deciding to participate in this program?
- 3) Do the ADC program staff seem to understand your own unique needs? Do they consider your cultural beliefs and values when you discuss your condition or treatment options? [PROBE: Do they understand challenges that you may have to making an appointment, your home situation, or other things that are important to you that may impact your healthcare or treatment?]
 - a. What could the ADC program staff do to better understand your values, your preferences for treatment, or your unique needs?
- 4) Has your primary care doctor's office or the ADC program staff invited you and/or your family to provide input on their office and ways they could improve your experience?
- 5) There are many ways that patients and doctors 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 do you take in your own care? [PROBE: Do you ask questions, share your views about what you think is best for you? Do you rely on your doctor to remind you to see a specialist?] How often do you and your provider discuss alternative treatments and therapies?
- 6) We now would like to ask some questions about the Next Steps Conversation. This conversation involves [DESCRIBE]. Did you participate in a Next Steps Conversation? If so, please describe.
 - a. How did you learn about Next Steps? What questions did you have?
 - b. What things did you like about this process? What could be improved?
- 7) What was your experience with the Statement of Treatment Preferences form?

- a. What role did you play in developing these documents?
 - b. How did the ADC team help you during the process? What things could be improved about the process of creating this document?
 - c. Is this document important to you? Why?
 - d. Who has copies of this document?
 - e. What things do you like about this document? What things could be improved about this document or about the process of creating it?
- 8) We now would like to ask some questions about advance care directives, or documents that summarize your wishes. These could include a statement of treatment preferences, a power of attorney for health care form, or a physician orders for life sustaining treatment (POLST) form. How did you learn about the document(s)? How long have you had your treatment preferences documented? Who on your care team helped you to develop the document(s)? What did you like about the process of creating the document(s)? What did you not like about the process or the document(s)? Why?
- 9) In what ways does the ADC team support you and your family in getting involved in your own care? [PROBE: Do your providers talk to you about your condition or treatment options in a way that is easy for you to understand? Does your provider explain the pros and cons of different treatment options? Are they willing to answer your questions?]
- 10) What does the ADC team do to help you take better care of yourself and your medical condition? [PROBES: Review the medications that you take, screen for more conditions, etc.] Do you like or dislike how they do things? Why?
- 11) Are you able to contact someone on your ADC team to answer your questions or assist you when your doctor is not available?

Next, we want to talk about how you get care from someone outside of the ADC team. For example, sometimes you may need to see a specialist– like a surgeon, heart doctor, allergy doctor, psychiatrist, foot doctor, or others who specialize in specific types of care.

- 12) Which providers other than your primary care doctor do you see for care? Probe on each provider and types of interactions that they have with them. [PROBES: What type of care did you receive from each of these providers (surgery, counseling, X-rays, chemotherapy, other medications, or other services?)
- 13) Does your ADC team play a role in getting you to a specialist? How do they help? [PROBES: Do they make referrals? Do they make the appointment for you?]
- a. How does this arrangement work out for you? What do you like or dislike about it?
 - b. Does your primary care provider know the results of your visit with a specialist? [PROBE: Do they refer to test or lab results or notes from the specialist?]
 - c. Does your ADC team include a specialist? Do you see one regularly that you feel should be a part of your ADC team?

- 14) When you go to your primary care doctor for a medical visit, does your doctor know if you've visited the emergency room, been hospitalized, or had a nursing home or rehabilitation stay since your last office visit?
- Does your primary care provider know about new prescriptions or procedures that were done?
 - How do you think they know?
 - Has this always been the case or have you noticed any changes in the past year or so?

15) Has anyone from the ADC team assisted you as you were admitted or discharged from the hospital?

- How did they help you?

16) Have you worked with palliative care providers at GLHS?

- How did they help you?

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

17) Do you have nurses in the ADC program that call you every so often, visit you at home, or that you can call when you have questions?

- How were you introduced to the nurses?
- When did the nurses start to work with you?
- How do the nurses help you? [PROBE: Have the nurses helped you manage your condition(s)? Have the nurses called you when you returned from the hospital? Has the [nurse] care manager helped you schedule a medical visit with a doctor?]
- How useful are the nurses?
- How do the nurses communicate with you? [PROBES: In-person at your doctor's office? Over the phone?] How often do they contact you?
- If you take medication, do the nurses help you understand your medication? If so, how useful is this?
- What did you like or not like about the nurses?

18) Do you work with a social worker through the ADC program?

[If yes...]

- How does the social worker help you?
- What kinds of resources and support does the social worker discuss?
- How does the social worker usually communicate with you?
- Do you feel comfortable discussing issues and challenges with the social worker?
- What did you like or not like about the social worker?

19) Have you 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?
- b. Did the ADC team reach out to your personal chaplain/counselor?

[If yes...]

- c. How does this person help you?
- d. What did you like or not like about the counselor/chaplain?

20) Has anyone on the ADC team (like a nurse or social worker) told you about non-medical services in your community? [PROBE: Such services may include Meals on Wheels, housing options, social activities at the local seniors' center]

- a. Do you receive services from any of these community resources?
- b. Has your primary care provider or someone else on your care team asked if you use any of those community resources? Did they ask you about your experiences with these resources?

21) 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?

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

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

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

These are all of my questions. Is there anything else you would like to share with me in regard to the ADC program that we haven't already discussed?

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