

Medicare Health Care Quality (MHCQ) Demonstration Evaluation

Guide for RTI Staff Conducting Focus Groups with Caregivers of Medicare Beneficiaries Participating in the Meridian Care Journey 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 members' experiences in receiving services from the Meridian Care Journey (MCJ) program at the Meridian Health System (MHS), and your own experiences with the MCJ program as well. Your experiences will help us understand how the MCJ 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 MCJ program.

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

B) Review focus group process and 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 people 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 information 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 Experience with Care

The primary purpose of today's discussion is to learn about the services provided to the person you care for by his/her primary care doctor and the Meridian Care Journey team at MHS. The Meridian Care Journey team may include nurses, social workers, or chaplains. They may call you or the person you care for on the phone to check in or make home visits. During the next two hours, I will be referring to these people as the "**Care Journey team.**" When answering questions, please think about the people on the Care Journey team and the services they provide.

Do you have any questions so far, especially about what we mean by the "Care Journey team?"

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 program called "Meridian Care Journey" (MCJ) 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 Care Journey team.

- 2) How did you learn about the MCJ program? [PROBES: Did the person you care for receive a letter from his/her doctor to tell him/her about the program? Did the person you provide care for tell you about the program?]
- 3) What helped the person or family member you care for to decide to participate in the MCJ 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 Care Journey team either separately or together with the person you care for? [PROBES: participate in physician visits; consult the care coordinator; what else?]
- 5) Do the MCJ program staff 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 MCJ 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 Care Journey team discuss different treatment options?

- 7) We now would like to ask some questions about advance care directives, a power of attorney for health care form (also called a health care proxy), or documents that summarize the living will of the person you care for. These could include a statement of treatment preferences, a physician orders for life sustaining treatment (POLST) form, or the 5 wishes. Does the person you care for have any of these documents? Did the person you care for participate in developing any of these advance care directives, living will, or POLST? Were **you** involved in that process? If so, please describe.
 - a. How did you and the person you care for learn about these advance care directives and treatment preferences options? How long has he/she had his/her treatment preferences documented? Who on the Care Journey team helped him/her to develop the document(s)?
 - b. What things did **you** like about this process? What could be improved?
- 8) How does the Care Journey team help you or the person you care for understand his/her condition or treatment options? Do they explain the pros and cons of different treatment options? Are they willing to answer questions?
- 9) How does the Care Journey team support the person you care for in getting involved in his/her own care?
- 10) What does the Care Journey team do to help you or the person you care for take better care of him/herself and his/her medical condition? [PROBES: Review the medications that he/she takes, screen for more conditions, discuss care planning etc.] Does the person you care for like or dislike how the Care Journey team does things? Do **you** like or dislike how they do things? Why?
- 11) How does the Care Journey 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?
- 12) Can you or the person you care for contact someone from the Care Journey team to answer his/her questions or assist when his/her doctor is not available? Are **you** able to contact someone on the Care Journey team to answer your questions?
 - a. Do they help the person you care for arrange to see his/her doctor when needed?

Next, we want to talk about how the person you care for seeks care from someone outside of the Care Journey team. For example, sometimes he/she 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.

- 13) What types of providers other than his/her primary care doctor does the person you care for usually see for 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.)?

- 14) How does the Care Journey team assist in getting the person you care for a referral or appointment to see a specialist? [PROBES: Do they make referrals? Do they make the appointment for you?]
- How does this arrangement work out for you and the person you care for? What do you like or dislike about it?
 - Does the primary care provider of the person you care for know the results of his/her visit with a specialist? [PROBE: Do they refer to test or lab results or notes from the specialist?]
- 15) When the person you care for goes to his/her primary care doctor for a medical visit, how does the doctor know if he/she has visited the emergency room, been hospitalized, or had a nursing home or rehabilitation stay since his/her last office visit?
- Does the Care Journey team know when the person you care for has visited the emergency room, been hospitalized, or had a nursing home or rehabilitation stay?
 - How does his/her primary care provider know about new prescriptions or procedures that were done?
 - How do you think they know?
- 16) Who from the Care Journey team assists the person you care for as he/she is admitted or discharged from the hospital?
- How did they help him/her?

We now would like to ask about experiences with different Care Journey team members, such as nurse practitioners, nurses, social workers, 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.

- 17) Has the person you care for worked with palliative care providers through the Care Journey program?

[If yes...]

- 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?
 - When did the palliative care providers start to work with the person you care for?
 - How do the palliative care providers help the person you care for?
 - How do the palliative care providers usually communicate with the person you care for? [Probe: In doctor's office, home visit, phone call] Do they communicate with **you**?
 - 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?
 - Does the person you care for receive care from palliative care providers outside of the Care Journey program?
- 18) Does the person you care for have nurses in the Care Journey program that call him/her every so often, visit him/her at home, or that you can call when you have questions?

[If yes...]

- a. How did the person you care for first meet these nurses?
 - 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?
- 19) Do you or the person you care for interact with a social worker through the Care Journey program?

[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, phonecall] Do they communicate with **you**?
 - c. What kinds of resources and support does the social worker discuss?
 - d. Does the person you care for feel comfortable discussing issues and challenges with the social worker?
 - e. 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?
- 20) Have you worked with a pastoral care counselor or chaplain through the Care Journey program?

[If no...]

- a. Have you heard about such service? [If yes] What were some of the reasons that you or the person you care for 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?
- 21) Has anyone on the Care Journey team (like a nurse or social worker) told you or the person you care for 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. Does the person you care for receive services from any of these community resources?
 - b. Has his/her primary care provider or someone from the Care Journey team asked if he/she uses any of those community resources? Did they ask him/her about his/her experiences with these resources?
- 22) What kinds of support and resources does the Care Journey program provide to **caregivers like you**?
- 23) Overall, what are some of the things that **you** like about the Care Journey program? What are some of the things about the Care Journey program you do not like? Do you think the MCJ program is beneficial? If so, why?
- 24) Would you recommend the Care Journey program to your friends? Why or why not?
- 25) If you could change or improve one thing about the Care Journey program, what would it be?
- 26) If the Care Journey 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 Meridian Care Journey program that we haven't already discussed?

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