

March 2016

Medicare Health Care Quality (MHCQ) Demonstration Evaluation

Meridian Health System

Patient and Family Member Focus Group and Interviews Report

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PATIENT AND FAMILY MEMBER FOCUS GROUP AND INTERVIEWS REPORT

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CMS Contract No. HHSM-500-2005-00029I

March 2016

This project was funded by the Centers for Medicare & Medicaid Services under contract no. HHSM-500-2005-00029I. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. RTI assumes responsibility for the accuracy and completeness of the information contained in this report.

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SECTION 1 INTRODUCTION

Meridian Health System's (MHS) Medicare Health Care Quality (MHCQ) Demonstration seeks to build a coordinated care system for chronic and late-life care patients with advanced diseases. To achieve this aim, the demonstration supports patients with advanced diseases and provides them with chronic disease management and palliative care in their homes and in nonacute community facilities. MHS nurse practitioners (NPs), registered nurses (RNs), social workers, and a chaplain engage the demonstration patients, their families, and primary care physicians (PCPs) in providing and coordinating medical services as well as addressing other needs of patients. This report summarizes findings based on a focus group and interviews conducted with demonstration patients and their family members, referred to as "participants."

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SECTION 2 METHODS

To gain an in-depth understanding of patient and family experiences with the demonstration, we conducted one focus group and 17 interviews with patients enrolled in the MHS demonstration and their family members. A total of 27 individuals participated in these discussions, including 18 demonstration patients and 9 family members who were involved in their care. The semistructured interviews and the focus group were conducted on November 2–4, 2015. The focus group was conducted at an MHS facility. Interviews were conducted at patient or family member residences, typically at home or in a nonacute community facility. Interviews were conducted by two teams of RTI researchers, with each team including an interviewer and a note-taker. Each interview was accompanied by an MHS staff member to respond to any unanticipated emotional or physical needs that might arise during the interviews.

RTI worked with MHS staff to select the interviewees to ensure that participants had appropriate cognitive and physical ability to participate, since many demonstration enrollees were severely ill, and that the interviewees represented a diversity of demonstration experiences in terms of duration in the program and types of services received. Each interview lasted 1 hour and the focus group discussion lasted 1.5 hours. Discussion questions sought to understand patient and family member experiences with the MHS demonstration services and staff. This study was reviewed and approved by the U.S. Office of Management and Budget.

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SECTION 3 FINDINGS

3.1 Joining the Demonstration

Most participants indicated that they learned about the demonstration during or shortly after a hospital stay or from their PCP during an appointment. Most shared that they joined the demonstration because it was free and would provide them with additional help at home. A couple who had been taking care of their mother with Alzheimer's at home for 10 years shared that they enrolled their mother in the MHS demonstration 2 years ago because

...we were overwhelmed, couldn't focus, were tired, and couldn't get out (of the house). It was a big blur, and you can't get that way if you are dealing with a sick person. There were so many things we didn't know. We were stuck here.

Some participants wondered why they were allowed to be in this demonstration while others, who they thought would greatly benefit, were not. All indicated they would strongly recommend the demonstration to others, but were unsure of how to do so.

3.2 Medical Services

Demonstration staff provided ongoing monitoring and support to participants' medical conditions. In addition to routine care services, staff also addressed medical needs not identified by other providers, by offering medical services or connecting participants to the appropriate resources. In many cases, such services resulted in identification of missed diagnoses, adjustments of inappropriate medication regimens, improved pain management, improved participant compliance, accountability, self-management, and assurance of safe environments at home.

Participants reported that the MHS demonstration staff provided services that they did not receive from physicians. Most participants reported that regular check-ups provided by demonstration staff at their homes allayed their fears because they knew a trained medical professional would catch anything serious that might be happening with their disease. Participants valued the amount of time that the demonstration staff would spend with them explaining their disease. Many shared that this education allowed them to manage their conditions better and keep them accountable for their own health because they knew the demonstration staff would be stopping by to check on them:

The [demonstration] staff always tell you to use your mind, to stay active and enjoy life. It is such a comforting situation. It's the spirit of the program to get you up eating, drinking water, staying in touch with the world—just living [long pause]—like any other person.

Participants also indicated that such interactions helped them to understand their diagnosis and decision-making, and motivated them to be more compliant with medical orders and recommendations. For example, a spouse of one participant, who was refusing to take his prescriptions and follow his physician's orders, shared that after several discussions with the

demonstration nurse, the participant became much more compliant because he understood what was being prescribed to him and why. In the participant's words,

When I know someone is checking on me, it makes me want to try harder (...) (My nurse practitioner) explains why I need to do certain things with my medication. I have to be convinced that changing things is worth it. She helps me accept the changes. Now, when I go see my doctor, I generally have an understanding of what he's going to change. It's easier to accept or reject what he's saying now that I meet with (my nurse practitioner).

Similarly, family members described that education and support provided by demonstration staff helped them to achieve better compliance and safety for the patient. One family member noted:

[The Nurse and Social Worker] back up that I'm not the bad guy. I can now tell [the demonstration participant] to use the walker and she will listen more now because they tell her the same thing.

Several participants observed that monthly check-ups reduced or prevented hospitalizations. One participant shared that most of her mother's hospitalizations occurred because she was not taking her medications, not drinking water, and not eating right; according to the participant, her mother had not been in the hospital since she joined the demonstration. A wife of another participant shared that her husband had several life-threatening hospitalizations due to aspiration pneumonia because he was not using his nebulizer due to pain and a swollen throat. Realizing that the patient was failing to comply with the prescribed regimen, the demonstration nurse engaged the patient in trying to understand the reasons for noncompliance, and suggested that he rinse out his mouth after using the nebulizer to wash away residual steroids in his throat that were causing irritation. Since then, the participant was able to use the nebulizer with no discomfort. According to his wife, this intervention not only prevented subsequent hospitalizations, it saved her husband's life.

Several participants shared that the demonstration staff helped them manage their pain. For example, one participant said that her nurse helped with stretches and exercises that reduced the pain in her legs, which enabled her to go outside and talk with her neighbors—something she had not been able to do for several years. Other patients shared that, as result of feeling less pain, they became more active.

Another demonstration feature valued greatly by participants was that the demonstration staff looked at “the whole picture,” including all of their medical and nonmedical needs. As one participant noted, “instead of different doctors, [the social worker] brought one person [the demonstration nurse] to address everything (...)” Participants observed that this holistic approach focused on all their needs and improved their overall well-being, making them feel healthy and optimistic about the future:

Nobody told you that you could be old and healthy. This program told me that you can be old and healthy. In this way, they have given me the hope and will to live.

Participants described many ways the demonstration staff helped them with their medications. Some noted that the demonstration staff connected them with a pharmacy that prepackaged their pills into individual time-stamped rolls so they did not have to sort their pills into pill boxes themselves. Many participants explained that medication reconciliation improved the quality and possibly duration of their lives or their loved ones' lives.

For example, the daughter of a 90-year old woman in a nursing home shared that before joining the demonstration, her mother was on more than 40 medications that had multiple interactions and side effects. Consequently, she was immobile, unresponsive, and unable to communicate: "That's what we used to call her, Zombie mom. She was on pretty heavy [opioid] medicine that she apparently didn't have to be." The demonstration nurse was able to reduce the number of medications to just a few pills a day and change some medications to nonopioids. At the time of the interview, the mother was actively engaged, even making occasional jokes. Her daughter said that she did not believe her mother would have been alive had the changes by demonstration staff not been made.

Trusting relationships with the demonstration staff allowed patients and family members to share issues they have dealt with for a long time and were not comfortable describing to other providers, many of which resulted in identification of missed or mismanaged diagnoses in the past. One participant noted that he was not comfortable telling his physician about rectal bleeding that he had for a prolonged time but was finally comfortable sharing it with the demonstration staff, whom he started to know and trust.

Many participants shared that the demonstration improved their mental health. One participant shared that at the time of joining the demonstration, he was no longer interested in living. Since joining the demonstration, he discovered meaning and joy in his life again and was looking forward to the future. His anxiety, depression, and other medical conditions were adequately addressed and he was comfortable enough to share his concerns with the demonstration social worker he trusted. He said that the social worker changed his attitude, and he now felt that life is worth living, attributing his optimism for living to the demonstration staff:

You [are] by yourself and nobody calls. If I didn't get their calls, I would get no calls day after day after day. (...) Now I feel like somebody is available (...) I don't want to give up now. Now that I got started, I want to keep getting better and having a positive attitude. (...) They've helped because they changed my attitude that life is worth living.

Several other participants also indicated that they had been diagnosed with depression since joining the demonstration, as demonstration staff identified the symptoms and coordinated the treatment with participants' primary care providers. All participants observed that their mental health improved because the demonstration staff assured them that everything was being looked after.

Family members of demonstration participants reported similar experiences and effects of the demonstration on their mental well-being. They shared that demonstration staff advised them of many resources, including mental exercises, stress coping techniques, and suggestions for family member support groups to help them better take care of themselves and their loved ones.

Many explained that these resources helped family members feel “less guilty” about taking time to recharge:

[Caring for elderly] is a heavy burden. [The social worker] eases my mind. I've been neglecting myself. Now she is helping me find a doctor for myself.

3.3 Care Coordination

Participants reported that their health care providers effectively exchanged information about their health, including exchanges between specialists and primary care doctors, between the MHS demonstration staff and medical providers, and between the Meridian hospitals and physicians. Several participants noted that demonstration staff also ensured that information was properly communicated to all involved providers and to the participant. In some cases, information exchange with specialists outside of the MHS was limited, because outside practices did not use the same electronic health record system. In those cases, demonstration staff ensured that such information was shared with all involved parties.

Participants described multiple ways the staff coordinated their care with PCPs, specialists, hospitals, and nursing homes. They shared that their social worker and NP would reach out to them during and after hospitalizations to discuss their case with hospital staff. Most participants indicated that the demonstration staff were automatically alerted if the participant visited the emergency room.

3.4 Other Services

Participants placed great value on many community resources and services that demonstration staff helped them use. Participants shared that staff taught them about services they did not know were available, helped to navigate the labyrinths of Medicare and Medicaid eligibility, coverage and requirements; helped to make arrangements with transportation services and affordable food programs; and identified respite programs for family members, medical equipment programs, prescription drugs programs, financial assistance services, and access to affordable cell phones. Participants viewed such services as crucial to their quality of life. As one participant summarized, the demonstration staff are there “when we don’t know what to do or where to go.”

For example, a few participants who required frequent blood drawings shared that their social workers connected them with a service that did blood drawing at patient homes. This service was extremely helpful because it enabled participants to comply with their doctor’s orders, relieved them from having to make transportation arrangements, and reduced the possible risk of falls. Several homebound participants noted that the demonstration staff connected them to a podiatrist who would visit participants in their homes. This made it less painful and more feasible for them to receive podiatric care because they did not have to use their feet or rely on others to get to their appointments.

Several participants noted that the program staff helped them to live independently by ensuring safety at home. Many participants shared that the demonstration staff assessed their homes to verify that everything was safe, and that staff offered suggestions on enhancements, such as bars and shower chairs in bathrooms, to prevent falls.

3.5 Assistance with End-of-Life Decisions

Demonstration staff also helped participants with documenting their end-of-life preferences. Participants described this process as valuable, yet daunting and distressing due to the magnitude these decisions would have on their life and the lives of their loved ones. Participants shared that the demonstration staff guided them through this process and calmed their anxieties in helping to navigate end-of-life forms such as living wills and Physician Orders for Life Sustaining Treatment (POLST) forms.

All participants indicated that having such documentation and knowing that their families would not have to make these decisions on their behalf made them feel more secure and relieved. Several indicated that they could not have completed many of these forms without the help of the demonstration staff because they did not always understand what the forms meant. For example, several shared they had preconceived notions that if they filled out the form, they would not be taken to the emergency department for treatment if they had an acute episode. Participants described how the staff helped them understand the content of the documents and the participants' role in their own medical decisions, whether it meant more or less intensive end-of-life efforts, and indicated that their wishes were respected and supported regardless of their decision. As shared by one participant,

They helped me face my mortality, which I was very afraid of. Now, I have all this support and feel so much better. I've made all the decisions for my living will with my two girls and other family members. We're all on the same page now that we've completed my living will. (...) I was able to face it. I'm not afraid anymore. (...) I probably would've put off the living will knowing my nature (...) I was afraid that if they took me in and I didn't want to be resuscitated that (the medical staff) wouldn't help me. (The demonstration) staff assured me that it wouldn't be like that. (...) It helped clear my mind. I found that extremely helpful. I feel they're my advocate.

While many demonstration participants completed a living will or POLST form, a few shared that they decided not to complete them. Some of these participants shared they were still confused about what exactly the form meant for them, while others said that they did not want to deal with these decisions at this time. Most of the participants that had not yet completed a living will or POLST form planned to complete one in the near future, once they felt more prepared.

3.6 Spiritual Needs and Services

Many participants indicated that their spiritual needs were as important as physical and mental health. Several shared they were no longer able to be part of their religious communities and attend the services because of relocations to a new area or inability to drive. Some were grieving a recent loss of a spouse, sibling, or friend, and had no ability to seek and receive comfort in religious service they relied on throughout their life.

One participant had to relocate from the community where she lived her entire life to an entirely new area due to a hurricane and flood. Shortly after moving to the new neighborhood, she lost her husband of 60 years. The participant did not know her neighbors and did not want to

ask her children to take her to church. The only spiritual outlet that she had for her grief was to watch religious services (masses) on television. The participant shared that, with the chaplain visiting her home, “I was gaining back what I have lost (...) I am always moving forward.”

When we interviewed participants, the demonstration chaplain had recently begun providing religious services to participants, and several participants described the benefits of having a chaplain as part of demonstration staff. Two participants indicated they were hesitant with the chaplain initially because they did not understand the intent of the service. Once they had a better understanding of chaplain’s role and affiliation with the demonstration, they gradually established a trusting and meaningful relationship. As with other demonstration services, the key to the chaplain’s role and building relationships was in making regular visits.

3.7 Communication

Participants valued having timely and effective communication with the demonstration staff. All participants knew how to get in direct contact with the staff and reach them in the timely manner when needed. Ongoing monthly contact developed trusting relationships between participants and staff. Having no end-date to demonstration participation established a sense of security and stability. As one participant indicated, demonstration staff “don’t leave you.” Family members enjoyed the same level of access and quality of services, regardless of whether they were providing direct care for the patient full time or lived some distance away.

All participants described having trusting relationships and clear communication with demonstration staff. They reported that the demonstration staff understood their needs and what they were going through, and answered any questions that they had about their needs. One participant relied on demonstration staff to read him his lab results and communicate with his physician via the patient portal because the portal did not have connectivity with reading software for the blind.

Demonstration staff were especially praised for their ability to develop a rapport with the participants. In words of one patient, “[The nurse] spoke to me like I am here.” Several mentioned that the demonstration staff were never late for their appointments and would keep them informed of delays as short as 5 minutes; this made participants feel respected.

Everything is helpful—their kindness, their understanding. They are punctual. When they say they’ll be here, they are (...). We have no control over aging, but my family has peace of mind because of this program.

Often, participants described their experiences with demonstration services in contrast to their experiences with physicians. Most indicated that their doctors were hard to reach and too busy to educate them enough about their disease, provide adequate preventive care techniques, or conduct thorough assessments. Participants characterized their typical communications with physicians as rushed, unclear, and impersonal:

I talk to (the demonstration staff) about a lot of things I wouldn’t talk to my doctor about because he would just brush it off.

Doctors tend to gloss over things; the (demonstration) staff explain things in detail. That's what's good about nurses, they explain everything—doctors don't do that. Sometimes the doctor just tells you to Google it.

(...) when (the demonstration staff) are here, we get answers. The doctors are busy. The doctors tell you what's wrong and then they have to leave. When you talk to [demonstration staff], you really have an angel on your shoulder.

[Nurses] explain everything. It gets more personal and it's a good thing. To doctors, you're just a number.

3.8 Engagement of Patients and Families

Another unique aspect of the MHS demonstration was its focus on and integration of participants' family members. Participants described having many diverse family situations and arrangements, whether living alone or with their families, having no children or children living great distances away, or having children and spouses trying to help but not knowing how or not realizing that the help was needed. Several participants shared that they valued independence and did not want to be a burden to anyone, and that the program helped them to achieve that:

My kids are far away and they're all busy. They're willing to help, but I don't want to be a burden. We want to be independent and the program, with the things it offers allows us to pretty much manage on our own. We want to be independent. The program provides those little things that help really do make a big difference.

Participants also shared that demonstration staff would find a gentle and effective way to integrate their families in their care, either through joint visits, phone calls during the visit, or sharing updates by mailing records of the most recent medical visit or the demonstration newsletter. For example, one participant described having several adult children living in the area, but was uncomfortable asking anyone for help and was having difficulty with purchasing meals and finding transportation. The demonstration staff and participant together called the participant's son, and gently described the situation and needs of the parent. After that call, the entire family became actively involved with their mother's transportation and meals; the family frequently joined the monthly meeting between participant and demonstration staff by phone.

Several participants reported that, prior to joining the demonstration, concerns about health and other problems dominated their interactions with their family members. They shared that after joining the demonstration, they could enjoy spending time with their children and grandchildren while not worrying as much about health problems and other concerns.

Demonstration staff empowered family members to be able to take care of both their loved ones and themselves. Several family members indicated that they chose to take care of their loved ones themselves because they found nursing home or other similar long-term care facilities neglectful. Most indicated that demonstration staff helped them to provide such care at home. For example, a husband caring for his wife with Alzheimer's shared that care at the nursing home she was in was neglectful and uncompassionate. He wanted to take care of his wife at home, but did not have the necessary skills or knowledge, especially since she used to be

the one taking care of all their household and family needs. Demonstration staff empowered him to take care of his wife at home with minimal contracted help. In his words, “It’s like a person walking down the street with a cane, you drop your cane, and no one is around. [The demonstration staff] are there, they help you when you drop your cane.”

Others shared that the demonstration staff helped them realize that a nursing home was the most appropriate option and aided them in finding a nursing home they were comfortable with. After such a transition, the demonstration staff continued to be involved and provide support:

[The demonstration] opened the door of hope. It took us a year to put her [mother] in the nursing home—we couldn’t do it—the guilt. Without [the demonstration’s] help checking out the nursing home, we couldn’t have done it, (...) we weren’t getting any sleep. (...) they taught us how to help ourselves (...) Meridian is hiring the right people with big hearts that are open.

SECTION 4 CONCLUSIONS

The Meridian Health System demonstration offers a holistic care approach. Meridian addresses patients' medical, nonmedical, and spiritual needs at the same time. Demonstration components that led to high levels of participant satisfaction with the demonstration were integration of social and spiritual services; diversity of demonstration provider teams; frequency of visits; continuity of personnel; longevity of services; integration of family members; and ability to meet the unique needs of the patients.

Services provided by the demonstration fill gaps that exist in care due to the fragmentation in our health care and social care systems. These services improved the MHS demonstration participants' well-being, self-care behaviors, understanding of the disease processes, and social and emotional support.

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**APPENDIX A:
INFORMED CONSENT FORMS AND FOCUS GROUP AND INTERVIEW
PROTOCOLS**

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Informed Consent to Participate in Research for Beneficiaries

Title of Research: Medicare Health Care Quality Demonstration Evaluation

You are being asked to participate in a research study. Before you decide if you want to take part in this study, you need to read this Informed Consent form so that you understand what the study is about and what you will be asked to do.

The Medicare Health Care Quality Demonstration Evaluation is a research study paid for by The U.S. Centers for Medicare and Medicaid Services. This study is being conducted by RTI International, a nonprofit research organization. The purpose of this study is to evaluate health care services provided under the demonstration.

If you agree to participate, you will be asked to participate in an interview that will last approximately one hour. You will be asked questions about the health care services you receive. If you are a caregiver, you will be asked about services provided to the person whom you care for and their experiences. We believe there are minimal risks to you from participating in this interview. Every effort will be made to protect your confidentiality, but this cannot be guaranteed. There are no direct benefits to you from participating in this study. The Institutional Review Board (IRB) at RTI international has reviewed this research.

Your decision to participate in this research study is completely voluntary. You can refuse any part of the study and you can stop participating at any time. You can refuse to answer any question.

If you have any questions about this study, you may call Michael Trisolini, the RTI project director, at 781-434-1752. If you have any questions about your rights as a study participant, you may call RTI's Office of Research Protection at 1-866-214-2043 (a toll-free number).

Your signature below indicates that you read the information provided above, have received answers to your questions, and have freely decided to participate in this research.

Date

Signature of Participant

Printed Name of Participant

Date

Signature of Person Obtaining Consent

Printed Name of Person Obtaining Consent

Informed Consent to Participate in Research for Beneficiaries and Caregivers

Title of Research: Medicare Health Care Quality Demonstration Evaluation

You are being asked to participate in a research study. Before you decide if you want to take part in this study, you need to read this Informed Consent form so that you understand what the study is about and what you will be asked to do.

The Medicare Health Care Quality Demonstration Evaluation is a research study paid for by The U.S. Centers for Medicare and Medicaid Services. This study is being conducted by RTI International, a nonprofit research organization based in North Carolina. The purpose of this study is to evaluate health care services provided under the demonstration.

If you agree to participate, you will be asked to take part in a focus group interview that will last approximately two hours. You will be asked questions about the health care services you receive. If you are a caregiver, you will be asked about services provided to the person whom you care for and their experiences. We believe there are minimal risks to you from participating in this interview. Every effort will be made to protect your confidentiality, but this cannot be guaranteed. We want to assure you that we will not quote you by name in any reports that are written and provided to CMS. There are no direct benefits to you from participating in this study. The Institutional Review Board (IRB) at RTI International has reviewed this research.

Your decision to participate in this research study is completely voluntary. You can refuse any part of the study and you can stop participating at any time. You can refuse to answer any question.

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Date

Signature of Participant

Printed Name of Participant

Date

Signature of Person Obtaining Consent

Printed Name of Person Obtaining Consent

Medicare Health Care Quality (MHCQ) Demonstration Evaluation

Guide for RTI Staff Conducting Focus Groups with Medicare Beneficiaries Participating in the Meridian Care Journey 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 from the Meridian Health System. Your experiences will help us understand how some of their programs work for patients and their caregivers.

My role is to guide our discussion and to encourage everyone to share their experiences at [name of the hospital].

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 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. 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 care that you receive from your primary care doctor and the Meridian Care Journey team working with your doctor. The Meridian Care Journey 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 "**Care Journey team.**" When answering questions, please think about the people on your Care Journey team and the services they provide.

Do you have any questions so far, especially about what we mean by your "Care Journey 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.]

Good, let's get started!

F) Focus group discussion questions:

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.

- 1) How did you learn about the MCJ 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 MCJ 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 MCJ 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 program staff do to better understand your values, your preferences for treatment, or your unique needs?
- 4) Have MCJ program staff invited you and/or your family to provide 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 advance care directives, or documents that summarize your living will. These could include a statement of treatment preferences, a power of attorney for health care form (also called a health care proxy), or a physician orders for life sustaining treatment (POLST) form, or the 5 wishes. 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?
- 7) In what ways does the Care Journey 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?]

- 8) What does the Care Journey 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?
- 9) Are you able to contact someone on your Care Journey 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 Care Journey 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.

- 10) 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?)
- 11) Does your Care Journey 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?]
- 12) 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?
 - a. Does your primary care provider know about new prescriptions or procedures that were done?
 - b. How do you think they know?
 - c. Has this always been the case or have you noticed any changes in the past year or so?
- 13) Has anyone from the Care Journey team assisted you as you were admitted or discharged from the hospital?
 - a. How did they help you?
- 14) Have you worked with palliative care providers at Meridian Health System?
 - a. How did they help you?

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

- 15) Do you have nurses in the Care Journey program that call you every so often, visit you at home, or that you can call when you have questions?
- a. How were you introduced to the nurses?
 - b. When did the nurses start to work with you?
 - c. 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?]
 - d. How useful are the nurses?
 - e. How do the nurses communicate with you? [PROBES: In-person at your doctor's office? Over the phone?] How often do they contact you?
 - f. If you take medication, do the nurses help you understand your medication? If so, how useful is this?
 - g. What did you like or not like about the nurses?

- 16) Do you work with a social worker through the Care Journey program?

[If yes...]

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

- 17) 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 were not interested to use this service?
- b. Did the Care Journey 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?
- 18) Has anyone on the Care Journey 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?
- 19) 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?
- 20) Would you recommend the Care Journey program to your friends? Why or why not?
- 21) If you could change or improve one thing about the Care Journey program, what would it be?
- 22) 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.]

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 interviewing 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 experiences in receiving services from the Meridian Health System. Your experiences will help us understand how some of their programs work for patients and their caregivers.

My role is to guide our discussion and to encourage everyone to share their experiences at [name of the hospital].

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 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. 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. 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 caregiver, how do you assist the person you care for? 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? [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 you care for to decide to participate in the MCJ program? Who was involved in that decision? 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**? Was it a shared decision to be a part of the program?
- 4) In what ways do **you** interact with the Care Journey team? [PROBES: participate in visits; what else?]
- 5) Do the MCJ program staff seem to understand the unique needs of the person 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 program staff do to better understand the values, preferences for treatment, or unique needs of the person you care for?
- 6) Have MCJ program staff invited the person you care for and/or you to provide ways they could improve your experience?
- 7) 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?
- 8) We now would like to ask some questions about advance care directives, or documents that summarize the living will of the person you care for. These could include a statement of treatment preferences, a power of attorney for health care form (also called a health care proxy), or a physician orders for life sustaining treatment (POLST) form, or the 5 wishes. How did the person you care for learn about the document(s)? 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)? What role did **you** play in developing the documents? 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 Care Journey team support the person you care for in getting involved in his/her own care? [PROBE: Do the providers talk to him/her about his/her condition or treatment options in a way that is easy to understand? Do the providers explain the pros and cons of different treatment options? Are they willing to answer his/her questions?]
- 10) In what ways does the Care Journey team support **you** in getting involved in the care of the person you care for?
- a. How does the Care Journey team help you to understand his/her condition or treatment options?
 - b. Are they willing to answer **your** questions?
- 11) What does the Care Journey team do to help 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, etc.] Do you like or dislike how they do things? Why?
- 12) Is the person you care for able to contact someone on 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 ADC 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?]
- a. How does this arrangement work out for you and the person you care for? 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 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?
- How does his/her 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?
- 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 at Meridian Health System?
- How did they help him/her?
- 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?
- How did the person you care for first meet these nurses?
 - When did the nurses start to work with the person you care for?
 - 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?]
 - How useful are the nurses?
 - 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, phonecall, 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 MCJ 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?
- 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.]