

Evaluation of the Multi-payer Advanced Primary Care Practice (MAPCP) Demonstration

Focus Group Guide for Caregivers of Beneficiaries

A. Welcome

Hello and thank you for agreeing to meet with us today.

My name is [] and I work for The Henne Group, an organization that conducts focus groups on a variety of topics. I would like to introduce [], who represents RTI International [or Urban Institute], a nonprofit research organization.

You have been asked to participate in this focus group because you told us that you are a caregiver for someone who is covered by Medicare, Medicaid, or both. You might be a family member or a friend who helps this person with health decisions and goes with them to their doctor appointments. Each of you has a card that lists the name of the person that you represent in this discussion and the name of the primary practice that this person usually visits.

We are working on a project funded by the Centers for Medicare and Medicaid Services (CMS). We want to learn about the experiences you have had as a caregiver for the person listed on your card. We especially want to hear about your experiences with their primary care practice—the one that is also listed on your card.

My role is to guide our discussion and to encourage everyone to share their experiences, as a caregiver, with the practice listed on the card. Some of you may even go to this same practice for your own health needs. But for the purposes of this discussion today, please think about your experiences with this practice in the caregiver role.

[Name] will be taking notes while we speak. [Name] will be observing our discussion from the room behind the glass so that we can have our discussion without distractions. These individuals are part of our research team. They will summarize the views that are shared in these discussions. We are conducting 6 such discussions in [name of the state] and 42 additional discussions in 7 other states.

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 others have said. In fact, if you have a different idea or feeling, we especially want to hear from you so we can better understand the different experiences that people have as a caregiver at the different practices in the area.

To make sure that we understand everything people say today, we are making an audio and video recording of this discussion, as well as taking notes. So we can hear everyone clearly, we ask that only one person speak at a time. Even if you disagree with what someone is saying, please allow that person to have a chance to speak about their experience 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. You can end your participation and leave the room at any time.

We will not share any of your comments with the person you care for, people who work at their primary practice, their insurance provider, or anyone else in such a way that you or the person that you care for can ever be identified. We will not list your name or the person you care for in any of the written notes or transcripts. We will not put any names in our 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 an opportunity to share their ideas and experiences.

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 from this guide. 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 or name tents 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...

The primary purpose of today's discussion is to learn about your experience as a caregiver with the primary care practice listed on the card and the providers that work there.

During the next two hours, I will be referring to "**the primary care practice**". When I say that, I am referring to the practice listed on your card. When answering questions, please think about the people who work at the practice listed on the card and the services they provide.

The **provider** at that primary care practice could be a doctor, but may also be a nurse practitioner or physician assistant. The person you care for may also receive services at the practice from case managers, pharmacists, social workers, or patient advocates.

Do you have any questions so far, especially about what we mean by primary care practice or providers?

I also will be referring to "the person you care for". When I say that, I am referring to the person listed on your card. When you answer my questions, please answer about that person.

I want to discuss one more important issue before we get started. Many of us enjoy talking about our health. However, the focus is on **your experience as a caregiver with that person's primary care practices and providers**. So please limit comments about his/her health or medical condition to facts that may have **affected** your experience. Please don't be offended if I ask you to clarify **how** his/her health or medical conditions shapes your experience with his/her providers or if I move the discussion along to the next topic. Do you have any questions? ANSWER.

Good, let's get started!

Caregiver's Role

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?]
 - a. 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?]
 - b. Did the primary care practice of the person you care for ask about your role in helping that person? Did they ask about any circumstances that could affect the way you care for him/her, such as how close you live to the person you care for?

The Primary Care Practice

2. People think about different things when picking out a primary care practice they want to go to for their basic medical care. We are interested in learning about how the person you care for selected his/her primary care practice that is listed on your card. Think back to when the person you care for first chose his/her current primary care practice. Why did he/she choose this practice? [POSSIBLE RESPONSES: PRACTICE WAS RECOMMENDED BY FRIENDS OR FAMILY, FOUND IT IN A COMMUNITY RESOURCE/DIRECTORY, CLOSE TO THEIR HOUSE, ACCEPTED MEDICAID/MEDICARE PATIENTS, ETC.]

Patient Engagement and Management

3. When the person you care for goes to his/her primary care practice for a medical visit, how well do the staff know his/her medical history and important health information? [PROBES: Does his/her provider know all the medications he/she is taking and asks about them at every visit? Does his/her provider ask about his/her nutrition and activity level? What staff are you thinking of when answering this question?] Do you have to remind the staff about the person's medical history or important health information at each visit?
 - a. When the person you care for last saw his/her provider, did the provider give you or the person you care for any instructions or things to work on between visits? [IF YES: Were written instructions provided?] Have they always done this or is this something that has changed in the past year or so?
 - b. In what ways did the provider involve **you** in the plan for the person you care for? [PROBES: Did they ask **you** how you could help with the plan? Did they ask **you** if you understood the plan?] Have they always done this or is this something that has changed in the past year or so?
4. Has the person you care for ever seen someone other than their usual provider at their primary care practice? [OBSERVE NODS and other affirmative responses] Did that other provider seem to know about **your role** as caregiver? Did they include **you** in the conversation? How do you think seeing a different provider affects the care that the person you care for receives?
5. What do the providers at the primary care practice of the person you care for do that helps **you** to take better care of the person you care for? [PROBES: Reviews the medications that he/she takes with you; gives you advice on nutrition/meal plans; teaches you ways to provide care; writes instructions for you; asks you about household hazards, such as scatter rugs that someone could trip or slip on.]
 - a. Have they always done this with you? If new, when did you notice this change?
 - b. What do you like about this? What are some things you don't like about how they are doing things? Why?

6. If the person you care for has a chronic condition like diabetes or high blood pressure, what does their provider do to help them manage it?
 - a. Does his/her primary care provider give him/her information, like lab results, showing how well he/she has managed that condition over the past 6 months or year? Does the provider also share this information with **you**?
 - b. Has anyone at your doctor's office arranged for **you** to attend a special class about managing the condition of the person you care for? This might be a class taught by nurse educators about diabetes, hypertension, or coronary artery disease.
 - c. Has your primary care practice worked with **you** to develop a care plan for the person you care for? What kind of information or instructions are in this care plan? [PROBES: Does it include personal, patient-centered health goals (e.g., "to live long enough to attend my son's wedding" or "to be able to walk to the mailbox without getting out of breathe")?]
 - d. What has been most helpful to **you** to manage the condition of the person you care for? What else could your provider do to help **you** manage their condition?

We've talked about how well providers at the practice of the person you care for knows his/her medical history and things they do to help you manage their health. But there may be other things providers should know about a patient in order to provide them with the best care possible. For example, not all patients like to hear about bad health news the same way, or they may have certain beliefs about whether a treatment option is the right one for them, given their cultural background.

7. How well do providers understand the unique needs of the person you care for? Do they consider his/her cultural beliefs and values when they talk to you or the person you care for about his/her health condition or treatment options? [PROBES: Do they understand challenges that you or the person you care for may have in making a weekly appointment or in getting care at a facility across town, language barriers, or other things that are important that may get in the way of the health of the person you care for?]
 - a. How could the providers at the primary care practice better understand his/her values, his/her preferences for treatment, or just understand his/her unique needs?
8. There are many ways that **caregivers and providers** can work together to manage the patient's health or medical condition. For example, some caregivers rely completely on the provider to know what is best for the person they care for, while others take a more active role in the decisions that affect the person they care for. How much of a role do **you** take in deciding how to best manage the health or condition of the person you care for? [PROBES: Do you ask the provider questions, share your views about what you think is best for them? Does the provider talk to you about the condition of the person you care for or his/her treatment options in a way that is easy for you to understand? Does the provider use medical words that are easy for you to understand?]
9. In what ways does the primary care practice of the person you care for support patients **and their caregivers** getting involved in their care? [PROBES: Does the provider of the person you care for talk to you about his/her condition or treatment options in a way that

is easy for **you** to understand? Does the provider explain the pros and cons of different treatment options? Is the provider willing to answer **your** questions? Are you able to access the medical record of the person you care for when needed?]

- a. Has this support been ongoing, or have you noticed that the practice has new ways to provide better support or improve communication with you or the person you care for?
- b. If this is a new way of communicating, when did you first notice the change?
- c. What do you think about these new practices? [PROBES: What do you like about them? What are some things that you don't like about them? Why?]

Access to Care

We've been talking about how you, the person you care for, and his/her provider have managed his/her care. Now we would like to hear about getting to see their provider. Remember, a provider could be a physician, nurse practitioner, or physician assistant. The person you care for may also receive services from case managers, pharmacists, social workers, or patient advocates working at the primary care practice.

10. How easy or hard is it for you or the person you care for to get an appointment when he/she needs one? [PROBES: Can they get a same day appointment for urgent needs? Can they get an appointment for nights, weekends, or holidays? Did the practice change its hours of operation? If so, how? Are the practice's hours more convenient for the person you care for?]
 - a. In what ways can appointments be scheduled with a provider? [PROBES: online through a patient portal, leaving a message at the clinic and someone calls back, scheduling an appointment before leaving the hospital.]
 - b. Has scheduling an appointment gotten better, worse, or about the same over the past year or so?
 - c. How are wait times for appointments? Have they gotten better or worse?
11. Some practices have added a patient portal to their website where patients and caregivers can access lab or test results, contact providers electronically, or schedule appointments electronically. Does the practice of the person you care for have a website that allows you to do any of these things? [PROBES: Have you used this website, online tool or patient portal?]
 - a. If uses: How easy is it to use? What do you like or dislike about it? What features do you use the most? What improvements, if any, would you suggest?
 - b. If doesn't use: Why not?
 - c. If the practice doesn't have one or don't know: Does this sound like something that you would find useful? Why or why not?

12. In the past year, have you noticed any other changes in the way the primary care practice is working now that makes it easier or harder for you to help the person you care for to get the care he/she needs, when he/she needs it?
- Has the practice added staff to help him/her get the care he/she needs? If so, what kind of staff have they added?
 - What do the staff do? [PROBES: Do they help you or the person you care for get timely referrals to specialists? Provide **you** with ways to take better care of the person you care for at home? Resolve other problems like getting necessary medical equipment or transportation to and from appointments? Provide more education about their health conditions? Have they helped **you** to transition the person you care for from the hospital or a skilled nursing facility to home?]
13. Sometimes people go to an emergency room instead of going to their primary care practice, even when they don't feel their injury or illness is life-threatening. For example, they may go to the ER for a sore throat or other routine services. In the past year, was the person you care for more or less likely to go to an emergency room for help that their primary care practice could provide?
- If less likely, why did this change?
 - Has the primary care practice of the person you care for done anything to help him/her avoid going to the emergency room? [PROBES: Has his/her provider or anyone else in the practice spoken with him/her or with you about ways to better manage his/her care or have they asked them or you to contact them before going to an ER? Has his/her doctor talked to you or the person you care for about when it is appropriate to go to an ER?]
 - Have any of these efforts changed the likelihood of the person you care for going to the ER next time?
 - Remember, we're talking about going to the ER for things that their primary care practice provider could take care of, not life threatening emergencies. What would need to change to encourage **you** to take the person you care for to get treated at their primary care practice instead of going to the ER?
14. How do you think any of the primary care office changes that we have talked about have affected the health of the person you care for?
- In what ways?

Care Coordination

Next, we want to get your opinions about how the care of the person you care for is handled when he/she needs to seek care from someone outside of his/her primary care practice. For example, sometimes patients may need to see a specialist to better handle their condition—a surgeon, heart doctor, allergy doctor, skin doctor, foot doctor, or another provider who specializes in specific types of care.

15. What role does their primary care practice play when he/she needs to see a specialist? [PROBES: Do they make referrals? Do they make the appointment for the person you care for or ask you to do it?]
- How does this arrangement work out for you and the person you care for? In what ways do you like it? In what ways do you dislike it?
 - Has his/her provider always played this role or is this something new? If new, when did you notice the change?
 - Does their provider know the results of their visit with a specialist? [PROBE: Do they refer to test or lab results or notes from the specialist during the next office visit?]
16. The person you care for may need to get lab work done, get an x-ray, or other tests during an office visit. How do you or the person you care for usually learn about the results of these tests? [PROBES: Who tells you or him/her about the results? How do they contact you or him/her? How soon do you or he/she usually find out?]
17. When the person you care for goes to his/her primary care practice for a medical visit, does his/her provider know if he/she has visited the emergency room, been hospitalized or had a nursing home or rehabilitation stay since their last office visit? Has this always been the case or have you noticed any changes in the past year or so?
- Do you think the primary care practice knows about new prescriptions or procedures that were done? Has this always been the case or have you noticed any changes in the past year or so? How do you think they know? Has this always been the case or have you noticed any changes in the past year or so?

For the following questions about care managers, the language in each state protocol will be tailored to reflect the appropriate terminology used in that state.
NC, MI, PA, NY, ME, VT: care manager; RI: nurse care manager; MN: Health Care Home services

Some services can be provided by others, such as a care manager, social worker, or someone else, either before or after an office visit, by phone, by email, or during a home visit. This person may teach you and the person you care for how to take better care of their medical condition, may have helped arrange a visit with another provider, or may have helped as the person you care for was admitted or discharged from a hospital, ER, or nursing home.

18. Does the person you care for have a care coordinator, care manager, social worker, or someone else who calls you or him/her every so often, or that **you** can call when you have questions?
- Is this person part of the practice staff or do they work for another organization?
 - If they work for another organization, how well does the [nurse] care manager coordinate the care of the person you care for with their primary provider or other staff at their primary care practice? [PROBES: Do they both seem to know what the

other is doing for their care? Do they each let the other know when the person you care for needs to see them?]

- c. How were **you** introduced to the [nurse] care manager?
 - d. When did **you** begin working with the [nurse] care manager on behalf of the person you care for?
 - e. How does the [nurse] care manager communicate with **you**? [PROBES: In-person at the provider's office? Over the phone?] How often do you talk with the [nurse] care manager?
 - f. How did the [nurse] care manager help **you**? [PROBES: Has the [nurse] care manager helped you manage care for the person you care for? Has the [nurse] care manager called you or the person you care for after they were in the hospital or nursing facility? Have they told you about resources that could help the person you care for? Have they coordinated care or scheduled appointments with other agencies or providers?]
 - g. If the person you care for takes medication, does the [nurse] care manager help you understand their medication? If so, how useful is this?
 - h. How useful was the [nurse] care manager?
 - i. What did you like or not like about the [nurse] care manager?
19. Care coordinators or social workers also may help you find resources in the community to help you in **your role as caregiver**. Has anyone at your primary care practice told you about any services or support groups for **caregivers**? [PROBES: Support groups that meet through the local hospital, local senior center, or through a place of worship? On-line support groups? Respite services that could relieve you of your daily responsibilities on occasion? Adult daycare options?]
- a. Have you already received services or support from any of these community resources? Which ones? How did you learn about these community resources? How useful are these resources?
 - b. Has the provider of the person you care for asked about **your** use of any of those community resources? Did they ask you about **your** experiences with these resources?

Insert Vermont and North Carolina state-specific questions

20. Has the primary care doctor's office invited the person you care for and/or you to provide feedback about their office or ways they could improve your experience? For example, were you or the person you care for asked to fill out a patient experience survey and/or participate in an advisory council? [NOTE TO FOCUS GROUP FACILITATOR: We are particularly interested in whether practices have gotten input from patients with a chronic condition, such as diabetes, high blood pressure, asthma for children, or patients who may have gone to the emergency department or been in and out of the hospital or nursing home].

Awareness of State Medical Home Initiative

[SOME STATES USE ANOTHER TERM FOR MEDICAL HOME. EACH STATE'S PROTOCOL WILL REFLECT THEIR OWN TERMINOLOGY. FOR EXAMPLE, MINNESOTA USES "HEALTH CARE HOME."]

21. Have any of you heard of the term "medical home"? What does "medical home" mean to you?

[Name of the state] has a plan that is designed to help primary care practices deliver better care to their patients. The term "medical home" doesn't actually refer to any one building or doctor. Medical home refers to a **team or network** of health professionals in different practices, hospitals, and support groups working together to provide better care to patients. The goal of a medical home is to provide better care to their patients by improving access and coordinating the many different kinds of health services provided by that team.

22. In [name of the state] it is called [name of initiative]. Have you heard about this initiative? Where did you hear about it or from whom? What have you heard about it? What is your understanding of the doctor's participation in [name of the state initiative or local network]?

23. Do you think that the health of the person you care for could improve under this type of model?

a. In what ways?

b. Are there any downsides to this model, as a patient?

These are all of my questions. Is there anything else you would like to share with me in regard to your role as caregiver and the care that the person you care for receives at his/her doctor's office that we haven't already discussed?

State-specific questions

North Carolina

[Insert question after Q18]

Some services can be provided by others, such as a clinical pharmacist, either before or after an office visit, by phone, by email, or during a home visit.

We now would like to ask about your experience with the clinical pharmacist. A clinical pharmacist is someone who meets with patients to discuss their medications. You may have met this pharmacist after the provider of the person you care for recommended them. Note this is not the pharmacist who is part of your local pharmacy where you buy medicines.

1. Have you met with a clinical pharmacist on behalf of the person you care for?

If yes....

a. How did you learn about the clinical pharmacist?

- b. How did the clinical pharmacist help you take better care of the person you care for?
- c. How useful was the clinical pharmacist?
- d. What did you like or not like about the clinical pharmacist?

Vermont

[Insert after Q18]

1. What other experiences have you had with the services in your community that might help the person you care for take better care of their health?

PROBES:

- Healthier Living Workshops
 - Tobacco cessation activities such as Quit in Person, or other parts of the Quit Network (Your Quit, Your Way, Quit On-line, Quit by Phone)
 - Wellness Recovery Action Plan (WRAP)—a standardized group intervention for adults with mental illness lead by trained co-facilitators who are peers
 - Family wellness coaching
- a. How did you learn about these community services?
 - b. How useful were these services?
 - c. Has the primary care provider asked you or the person you care for if they have used any of those community resources? Did they ask you or him/her about their experiences with these resources?