

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

Focus Group Guide for 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.

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 with the primary care practice listed on the card that you received when you signed in. [Card will list the beneficiary's name and their primary care practice name, based on claims data]

My role is to guide our discussion and to encourage everyone to share their experiences with the primary care practice listed on your card. [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 with their primary care practice.

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 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 your doctor, your insurance provider, or anyone else in such a way that you can ever be identified. We will not list your name in any of the 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 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 the care that you receive from 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.

Your **provider** at your primary care practice could be a doctor, but may also be a nurse practitioner or physician assistant. You 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 want to discuss one more 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 practices 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 shapes your experience with providers or if I move the discussion along to the next topic. Do you have any questions? ANSWER.

Good, let's get started!

The Primary Care Practice

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

Patient Engagement and Management

2. When you go to your primary care practice, how confident are you that the provider knows your medical history and important health information? Has this always been the case? [PROBES: Does your provider know all the medications you are taking and ask about them at every visit? Does your provider ask you about your nutrition and activity level? What staff are you thinking of when answering this question?]
 - a. When you last saw your provider, did he/she give you any instructions or things to work on between visits? [IF YES: Were written instructions provided?] Have they always done that or is this something that has changed in the past year or so?
3. Have you ever seen someone other than your usual provider at your primary care practice? [OBSERVE NODS and other affirmative responses] Did that other provider seem to know about things you discussed with your usual provider? How do you feel about seeing a different provider? How do you think seeing a different provider affects the care you receive?
4. What do the providers at your primary care practice do that helps you to take better care of yourself? [PROBES: Reviews the medications that you take; makes sure that you are up to date on your immunizations (shingles, flu shot, pneumovax); does regular screenings for diseases like breast cancer, colon cancer, or heart disease (or refers you to a specialist); asks questions about your energy level, your appetite, or how well you sleep? Gives you advice on nutrition or meal plans?]
 - a. Have they always done this or is this a new way they are giving care? 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?
5. If you have a chronic condition like diabetes or high blood pressure, think about what your provider does to help you manage it.
 - a. Does your provider give you information, like lab results, showing how well you've controlled that condition over the past 6 months or year?
 - b. Has anyone at your doctor's office arranged for you to attend a special class about managing your condition? 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? 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 your condition? What else could your provider do to help you manage your condition?

We've talked about how well providers at your practice know your medical history and things they do to help you manage your 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.

6. How well do providers at your primary care practice understand your own unique views? Do they consider your cultural beliefs and values when they talk to you about your health condition or treatment options? [PROBE: Do they understand challenges that you may have to making a weekly appointment or to getting care at a facility across town, language barriers, or other things that are important to you that may get in the way of your health care?]
 - a. How could the staff at your primary care practice better understand your values, your preferences for treatment, or just understand your unique needs?
7. There are many ways that patients and providers can work together to manage the patient's health or medical condition. For example, some patients rely completely 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? Rely on your doctor to remind you to see a specialist?]
8. In what ways does your primary care practice support patients and their caregivers getting involved in their own care? [PROBE: Does your provider talk to you about your condition or treatment options in a way that is easy for you to understand? Does your provider use medical words that are easy for you to understand? Does your provider explain the pros and cons of different treatment options? Does your provider listen carefully to your concerns? Is your provider willing to answer your questions?]
 - a. Has this support been ongoing, or have you noticed that your practice has new ways to provide better support or improve communication with you?
 - 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? [PROBE: 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 and your provider have managed your care. Now we would like to hear about getting to see your provider. Remember, a provider could be a physician, nurse practitioner, or physician assistant. You may also receive services from case managers, pharmacists, social workers, or patient advocates working at your primary care practice.

9. How easy or hard is it for you to get an appointment with a provider at this practice when you need one? [PROBES: Can you schedule a same day appointment for urgent needs? Can you schedule 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 you?]

- a. What ways can you can now schedule an appointment? [PROBES: online through a patient portal, leaving a message at the clinic and someone calls you back, scheduling an appointment before you leave the hospital.] What do you think about these different ways of scheduling an appointment? [PROBES: What do you like about it? What are some things you don't like about it?]
 - b. Has scheduling an appointment gotten better, worse, or about the same over the past year or so? How has it gotten better or worse?
 - c. How are wait times for your appointments? Have they gotten better or worse?
10. Some practices have added a patient portal to their website where patients can access lab or test results, contact their providers electronically, or schedule appointments electronically. Does your practice 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?
11. In the past year, have you noticed any other changes in the way your primary care practice is working now that makes it easier or harder for you to get the care you need, when you need it?
- a. Has your practice added staff to help you get the care you need? If so, what kind of staff have they added?
 - b. What do the staff do? [PROBES: Do they help you get timely referrals to specialists, provide you with ways you can take better care of yourself at home, resolve other problems like getting necessary medical equipment or transportation to and from appointments? Provide more education about your health conditions? Have they helped you transition from the hospital or a skilled nursing facility to home?]
12. 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, were you more or less likely to go to an emergency room for help that your primary care practice could provide?
- a. If less likely, why did this change?
 - b. Has your primary care practice done anything to help you avoid going to the emergency room? [PROBES: Has your provider or anyone else in the practice spoken with you about ways that you can better manage your care or have they asked you to contact them before going to an ER? Has your doctor talked to you about when it is appropriate to go to an ER?]

- c. Have any of these efforts changed your likelihood of going to the ER next time?
 - d. Remember, we're talking about going to the ER for things that your primary care practice provider could take care of, not life threatening emergencies. What would need to change to encourage you to get treated at your primary care practice instead of going to the ER?
13. How do you think any of your primary care office changes that we have talked about have affected your own health?
- a. In what ways?

Care Coordination

Next, we want to get your opinions about how your care is handled when you need to seek care from someone outside of your 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.

14. How does your primary care practice play a role in getting you 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? In what ways do you like it? In what ways do you dislike it?
 - b. Has your provider always played this role or is this something new? If new, when did you notice the change?
 - c. Does your provider know the results of your visit with a specialist? [PROBE: Do they refer to test or lab results or notes from the specialist during the next office visit?]
15. You may need to get lab work done, get an x-ray, or other tests during your office visit with a specialist. How do you usually learn about the results of these tests? [PROBES: Who tells you about the results? How do they contact you? How soon do you usually find out?]
16. When you go to your primary care practice for a medical visit, does your provider know if you've visited the emergency room, been hospitalized or had a nursing home or rehabilitation stay since your last office visit?
- a. Do you think your primary care practice knows 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?

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 [do not ask this question of VT SASH or Medicaid VCCI groups—these special populations have state-specific tailored questions]; 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 how to take better care of your medical condition, may have helped arrange a visit with another provider, or may have helped as you are being admitted or discharged from a hospital, ER, or nursing home.

17. Do you have a care coordinator, care manager, social worker, or someone else who calls you every so often, or that you can call when you have questions?
 - a. Is this person part of the practice staff or do they work for another organization?
 - b. If they work for another organization, how well does the [nurse] care manager coordinate your care with your primary provider or other staff at your primary care practice? [PROBES: Do they both seem to know what the other is doing for your care? Do they each let the other know when you need to see them?]
 - c. How were you introduced to the [nurse] care manager?
 - d. When did you begin working with the [nurse] care manager?
 - e. How does the [nurse] care manager communicate with you? [PROBES: In-person at your provider's office? Over the phone?] How often do you talk with your [nurse] care manager?
 - f. How did the [nurse] care manager help you? [PROBES: Has the [nurse] care manager helped you manage your chronic disease(s)? Has the [nurse] care manager called you after you were in the hospital or nursing facility? Have they coordinated your care or scheduled appointments with other agencies or providers?]
 - g. If you take medication, does the [nurse] care manager help you understand your 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?

18. Care coordinators or social workers also may help you find resources in the community to better manage your care. These people could help you if you are experiencing some sadness or challenges in your life, need help getting to the grocery store or the pharmacy or need help with other basic needs. Has anyone at your primary care practice told you about non-medical services in your community that they thought you could benefit from? [PROBES: Meals on Wheels, housing support, social activities at the local seniors' center, support groups?]

- a. Do you already receive services from any of these community resources? Which ones? How did you learn about these community resources? How useful are these resources?
- b. Has your provider asked if you have used any of those community resources? Did they ask you about your experiences with these resources?

Insert Vermont and North Carolina state-specific questions

19. Has your primary care doctor's office invited you and/or your family to provide feedback about their office or ways they could improve your experience? For example, were you 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."]

20. 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.

21. 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 your doctor's participation in [name of the state initiative or local network]?

22. Do you think that your health 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 the care that you receive at your 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 following a referral from your doctor or someone else in your doctor's office. Note this is not the pharmacist who is part of your local pharmacy where you buy your medicines.

1. Have you met with a clinical pharmacist?

If yes....

- a. How did you learn about the clinical pharmacist?
- b. How did the clinical pharmacist help you?
- 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 you to take care of your 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 your primary care provider asked you if you have used any of those community resources? Did they ask you about your experiences with these resources?

SASH module (for special population group)

We are also interested in experiences you may have had with a program called SASH. SASH stands for Support and Services at Home. SASH has staff in your housing unit or a housing unit in your neighborhood.

1. Are you aware of the SASH program?
 - a. If so, can you tell us about what types of services or programs are available?
 - b. How did you learn about SASH services or programs?
2. Have you used any SASH services or educational programs?
 - a. How actively do you participate? Did you sign a consent form to allow for coordination of care with their providers? If not, why not?
 - b. What services have you used? PROBES:
 - Coordination with providers or others in the provider practices such as social work, mental health provider, etc.
 - Coordination with Program of All-inclusive Care for the Elderly or PACE, home health agencies, Agency on Aging, Medicaid, others
 - Nutritional counseling
 - Medication management
 - Obtaining assistance for performing Activities of Daily Living (ADLs), self-care of medical or mental health conditions, including pain management
 - Healthy aging plans
 - Assistance transitioning home from the hospital (Skilled Nursing Facility or rehab facility)
 - Assistance transitioning to assisted living or long term care facilities
 - Assistance with transportation for health care services
 - Assisting with falls prevention
 - Others?
 - c. What educational programs you have participated in? [PROBES: diabetes, nutrition, healthy aging, exercise, others?]
3. How frequently do you interact with the SASH program coordinator or the wellness nurse?
 - a. What are the reasons for these interactions? What benefits do you feel you gained from these interactions?
 - b. Does your family or caregivers interact with SASH staff? If so, for what reasons? Is this beneficial to you?
4. What benefits do you see in this type of program?
 - a. What kind of residents would benefit the most?
5. What services or programs would you like to receive but that are not available from the SASH program?

Medicaid VCCI group module (for special population group)

We now would like to ask about your experience with your Medicaid care manager (through the Vermont Chronic Care Initiative (VCCI)).

1. How frequently do you interact with your care manager?
2. What are the reasons for these interactions or what services does your care manager provide?
 - a. Coordination with providers or others in the provider practices such as social work, mental health provider, etc.
 - b. Coordination with Program of All-inclusive Care for the Elderly or PACE, home health agencies, Agency on Aging, Medicaid, others
 - c. Medication management
 - d. Obtaining assistance for performing Activities of Daily Living (ADLs), self-care of medical or mental health conditions, including pain management
 - e. Assistance transitioning home from the hospital (Skilled Nursing Facility or rehab facility)
 - f. Assistance transitioning to assisted living or long term care facilities
 - g. Assistance with transportation for health care services
 - h. Others?
3. What benefits do you feel you gained from these interactions?
4. Do you also have interactions with any care managers in your physician's practice?
 - a. For what services? Do the two coordinate?
5. Is there anything else you would like to tell us about your Medicaid care manager?