



PACT Caregiver Focus Group Guide:

For Caregivers of Patients with a Recent Visit or Other Encounter to the Primary Care Clinic

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Introduction

Hello and welcome. Thank you for taking the time to come here and talk about your experiences with and opinions about the care the Veterans you know receive here. You've been asked to participate in this discussion because you were identified by a Veteran as someone who provides help and support for his/her health and conditions. We need your input because we are making some changes to improve the way we deliver care to Veterans. These changes are part of what we call the Patient Aligned Care Teams (PACT). I'll be covering several main topic items and I'll be moving the discussion from one question to the next. We're going to cover a lot of ground. I hope you'll talk with one another and not just to me. Sometimes in these groups, some people talk a lot and some people don't say much. But it is important for us to hear from each of you because you have different experiences. So if you aren't saying much, I may ask for your opinion. There are no wrong answers. People have different experiences and points of view and we want to hear them all. Please feel free to share your point of view even if it is different from what others have said.

Icebreaker

Please tell us: Your relationship to the Veteran and how long the Veteran has been coming here for care

I. Self-management support / informal disease management

First, we would like to talk about ways you help your friend or family member take care of his/her health condition.

- What do you do to provide help and support for your friend or family member's management of their illness?
 - What kind of support do you provide to him or her to help with his/her medicines?
 - If your friend or family member checks his/her blood pressure or weight, how do you get involved with this?
 - Do you get involved with making appointments, organizing their medical appointment schedule, or helping the Veteran prepare for appointments? How?
- When there are danger signs that your friend or family member's illness could be getting worse, what do you do?
 - What role do you play in helping him/her decide what to do?
 - Has anyone helped your friend/family member plan ahead of time, what they'll do if their condition seems to be getting worse? If YES, how have you helped?
- When your friend/family member feels sick what do you do?
- How does getting involved in your friend/family member's care affect you? Your friend/family member?
- What other family members or friends are involved; how are they involved?
- Describe a time when you were helping your friend/family member care for his/her condition and you were not sure that you were doing the right thing? Why did you feel that way? What would you need to feel more confident?
- What could the VA do to better support you as you help your friend or family member manage his/her illness?
- What would get in the way of you participating in these ways? How could the VA help you overcome those difficulties?

II. Friend/Family Experience with Primary Care

We're interested in hearing about your experiences coming to your friend or family member's primary care appointments here at the VA

- How do you feel about coming with your friend/family member to his/her primary care medical visits? Why?

- o Do you accompany your friend/family member to his/her primary care medical visits? Why or why not? What makes it difficult for you to come to appointments?
- When you come with your friend/family member to his/her appointment, what is that experience like for you?
- What could the VA do to help you participate in and contribute to your friend or family member's care during primary care visits?
- Is it your experience that your friend/family member's primary care doctor is part of a team?

III. Friend/Family Experience with VA Care Transitions

- For those of you whose Veteran family member/friend stayed overnight in a hospital in the last year, we'd like to know more about your experiences when they left the hospital.
 - o Were you involved decisions about what would happen after your friend/family member left the hospital?
 - If YES, how were you involved?
 - If NO, why do you think you were not included?
 - o Were you provided with enough information about your friend/family member's care and medicines? How could this be improved?
 - o Were you informed about what symptoms you need to watch out for to know if your friend/family member is getting worse?
 - If YES, who told you/how did you know?
 - If NO, why do you think this information was not provided?
 - o Was it clear which doctor/provider you should call if you had questions or problems when your friend/family member left the hospital?
 - o When you left the hospital did you know what should happen next?

IV. Caregiver-provider communication

- Have any of you talked with your friend or family member's doctors or nurses over the phone? How did that happen? What did you talk about?
- What has your experience been like communicating with VA doctors or nurses by phone or by email?
- How could the VA make it easier for you to communicate with your friend/family member's doctors or nurses?
- Would you like your friend/family member's VA doctors or nurses to take the initiative to contact you more often? Why or why not?

V. Family Use of VA Technology

- Do you ever help the Veteran communicate with the VA using the secured messaging (email), automated phone calls, telehealth, or the phone?
 - o If YES, how often and for what health situations?
 - o Would you like to use these technologies more? Do you think your friend/family member would like to use these types of technologies? How would you feel about helping your friend/family member use these technologies?

VI. Navigator System

- There is a nurse who helps patients find out about VA programs that are available to help with managing their conditions. This nurse talks with patients to understand what their needs and preferences are, and then match them to programs they want to enroll in. Some of these programs may involve caregivers such as you helping your family member or friend.
 - o Do you think this would be useful to you in your support of the patient? How so?

- o What do you think is important for the nurse navigator to know about you (the caregiver) so the nurse can match the patient with programs that will best support you and the patient in reaching the patient's health goals?

VII. Wrap Up

- What else is important to know about the friends and family members who provide support and care for veterans?