

## **Appendix**

### **Patient Interview Guide**

#### **Introduce interviewer and note taker.**

Thank you for taking the time to talk with us today. We are asking for your input because we are planning new programs that might change the way we support people with health conditions that they care for from day-to-day, like diabetes. One of our goals is to better include and support any family or friends who get involved with your health care. We asked you to talk with us because you have experience managing diabetes, and you have at least one family member or friend who takes an interest in your health care. Over the next 60 minutes, I'll be asking you several questions. There are no wrong answers. People have different experiences and points of view, and we want to hear them all. We are audio-recording this discussion because we don't want to miss any of your comments. We also may take some notes so that we can follow up on something you said later on. We'll use only our first names today, and there will not be any names in our reports. Your comments will be kept confidential, including from your family member. Your participation is voluntary and you can ask to skip a question or to stop the interview at any time. We will mail you a \$20 gift card to Meijers after the interview as a thank you for your participation.

<p>Patient – Caregiver Attributes: First, I'd like to get some information on your living situation and who is involved with your health care.</p> <ul style="list-style-type: none"> <li>• First, can you tell me who you live with?</li> <li>• Who gets involved with your health care?</li> <li>• Where do those people live?</li> <li>• The person that is most involved – are they working? Full time or part time? What shift? What type of job (desk job vs. customer service, etc)?</li> </ul>	
<p>Next, can you tell me a little about how you manage diabetes:</p> <ul style="list-style-type: none"> <li>• Do you use insulin (shots)?</li> <li>• Do you check your sugar at home?</li> </ul> <p>What is your biggest challenge in managing your diabetes?</p>	
<p>Next, we are interested to hear how your family members try to help you with your health care in certain ways.</p>	<p><i>Themes to follow-up on if they come up when discussing below:</i></p> <ul style="list-style-type: none"> <li>○ <i>Family/friends who <b>don't live with</b> patient</i></li> <li>○ <i><b>More than one</b> family member</i></li> <li>○ <i>How family encourage/discourage <b>patient autonomy</b> (respect patient's decisions, patient feels in charge)</i></li> </ul>
<ol style="list-style-type: none"> <li>1. Do your family/friend ever come into the exam room for your visits with their doctor or nurse?</li> <li>2. Think back to the last time your family/friend came into the room for your appointment. Describe what happened at the visit (probe for FF involvement if not readily apparent)</li> <li>3. How do you and your family/friend choose which appointments they will come [in the room] for?</li> </ol>	<ul style="list-style-type: none"> <li>○ <b>What do they do</b> during the visit?</li> <li>○ How does it <b>help you</b> when your FF come in the room?</li> <li>○ Have you ever <b>felt uncomfortable</b> that your FF was in the room? Why? <ul style="list-style-type: none"> <li>▪ <i>Feel welcomed, feel listened to, allowed to hear info, difficult for doctor, disagree with doctor</i></li> </ul> </li> <li>○ When your family or friends don't come in the room <b>why don't they?</b></li> <li>○ <b>Would it be helpful if</b> your FF came into your visits more often? Why/why not?</li> </ul>
<ol style="list-style-type: none"> <li>4. If there is a visit that your family/friend doesn't attend, do they ask you afterwards about what happened at the visit?</li> </ol>	<ul style="list-style-type: none"> <li>○ Describe how you share the information with them (incl printout from VA, written down, verbally).</li> <li>○ How confident are you that you remember everything important that happened?</li> </ul>

	<ul style="list-style-type: none"> <li>○ How confident are you that your explanation is accurate (i.e. you are remembering correctly what the doctor or nurse said)?</li> </ul>
<p>5. What do you do to get ready for your doctor visits?</p> <p>Does your family/friend ever help you? <i>For example:</i>  <i>Suggest or write down questions for you to ask the doctor/nurse</i>  <i>Remind you to bring my sugar log or other information</i></p>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b></li> <li>○ How does it <b>help you</b> when your FF helps you prepare?</li> <li>○ Have you ever wished that your FF would get <b>less involved</b> with preparing for visits?</li> <li>○ <b>Would it be helpful if</b> your family or friends would get more involved with helping you prepare for visits?</li> <li>○ <b>How is it difficult</b> for your family or friends to help you prepare for visits?</li> </ul>
<p>6. Have you ever needed to call your doctor or nurse on the phone when you have a problem or need something? If yes, please describe the situation.</p> <ul style="list-style-type: none"> <li>○ Does your family/friend ever talk to your doctor or nurse on the phone? In what situations? Please tell me about the last time this happened.</li> </ul>	<ul style="list-style-type: none"> <li>○ How does it <b>help you</b> when your FF talks to your doctor or nurse on the phone?</li> <li>○ Have you ever <b>felt uncomfortable</b> when your FF talks to your doctor or nurse on the phone?</li> <li>○ <b>Would it be helpful if</b> your family or friends talked to your doctor or nurse on the phone more often?</li> <li>○ <b>What makes it difficult</b> for your family or friends to call your doctor?</li> </ul>
<p>7. Does your friend/family member ever help you figure out how to use the VA?</p> <p><i>For example:</i>  <i>How to make appointments or use the pharmacy at the VA</i>  <i>Who to call at the VA when you have a question</i>  <i>What VA health programs you could sign up for</i></p>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b></li> <li>○ How does it <b>help you</b> when FF help you use the VA?</li> <li>○ Has there ever been a time when your family/friend didn't have <b>enough information</b> or the 'right' information about using the VA?</li> <li>○ <b>Would it be helpful if</b> your family or friends helped you more with figuring out how to use the VA?</li> <li>○ <b>What makes it difficult</b> for your family or friends to help you figure out how to use the VA?</li> </ul>
<p>8. How do you keep track of your medical information? (like test results or reports from non-VA doctors)</p> <ul style="list-style-type: none"> <li>○ Do you feel you need to keep track of it?</li> <li>○ Does your family member/friend ever help you keep track of medical information</li> </ul>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ How does it <b>help you</b> when FF keep track of your medical information?</li> <li>○ Have you ever <b>felt uncomfortable</b> that your FF is helping you keep track of your medical information?</li> <li>○ <b>Would it be helpful if</b> your family or friends helped you keep track of your medical information more?</li> </ul>

	<ul style="list-style-type: none"> <li>○ <b>What makes it difficult</b> for your family or friends to help you keep track of your medical information?</li> </ul>
<p>9. Do you use any VA computer programs? (like MyHealthVet, telehealth, secure messaging)</p> <ul style="list-style-type: none"> <li>○ Does your family member/friend ever help you use VA computer programs</li> </ul>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ Have you ever <b>felt uncomfortable</b> that your FF are helping you with VA computer programs? Why?</li> <li>○ Have you ever had an instance when your family/friends didn't have <b>enough information</b> or the 'right' information about this?</li> <li>○ <b>Would it be helpful if</b> your family or friends helped you use VA computer programs more often?</li> <li>○ <b>What makes it difficult</b> for your family or friends to help you use VA computer programs?</li> </ul>
<p>10. Do you ever go to non-VA hospitals?</p> <ul style="list-style-type: none"> <li>○ If yes, how do you figure out what to do next, e.g., send information to the VA? <ul style="list-style-type: none"> <li>▪ Does your family member/friend ever help you with this?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ Alternate: Have you ever had an instance when your family/friends didn't have <b>enough information</b> or the 'right' information about this?</li> <li>○ <b>Would it be helpful if</b> your family or friends helped you get your information to the VA after you go to a non-VA hospital?</li> <li>○ <b>How is it difficult</b> for your family or friends to help you get your information to the VA?</li> </ul>
<p>11. How do you manage your medicines?</p> <ul style="list-style-type: none"> <li>○ How does your family member/friend get involved with your medicines? <i>For example:</i> <i>Ask you if you took your medicines</i> <i>Help you refill your medicines</i> <i>Help you draw up or inject your insulin</i></li> </ul> <p>12. Has there been a time in the past when your diabetes medicines changed? <i>Focus on starting insulin or changes in insulin.</i> Describe to me what happened (probe for family/friend involvement if needed).</p>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ How does it <b>help you</b> when FF get involved with your medicines</li> <li>○ Have you ever had an instance when you wished your family/friends had <b>more information</b> or the 'right' information about your medicines?</li> <li>○ <b>Would it be helpful if</b> that your family or friends got more involved with your medicines?</li> <li>○ <b>How is it difficult</b> for your family or friends to get involved with your VA medicines?</li> </ul>
<p>13. How do you monitor your sugar at home?</p> <ul style="list-style-type: none"> <li>○ How does your family member/friend get involved with your home sugar readings?</li> </ul> <p>14. How do you handle it when your sugars are high?[probe for family/friend involvement]. How</p>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ How does it <b>help you</b> when FF get involved with your sugar readings?</li> <li>○ Do you ever feel uncomfortable when your FF get involved with your sugar readings?</li> </ul>

<p>did you arrive at that system for dealing with high sugars? [i.e. figured it out on own –with what information sources, nurse gave them algorithm, etc.?)</p> <p>15. Has there been a time when your sugars were out of control for a while, and you [and your doctor] had to figure out what to do about it? Describe to me what happened (probe for family/friend involvement if needed).</p>	<ul style="list-style-type: none"> <li>○ Alternate: Have you ever had an instance when your family/friends didn't have <b>enough information</b> or the 'right' information about how to manage sugar readings?</li> <li>○ <b>Would it be helpful if</b> your family or friends got more involved with managing sugar readings?</li> <li>○ <b>How is it difficult</b> for your family or friends to get involved with managing sugar readings?</li> </ul>
<p>16. Does your family member/friend help you decide what to do when you feel sick? <i>For example:</i> <i>Help you when your sugars go too low // cold or the flu</i></p> <p>17. Has there been a time in the past when your family member/friend got more involved than usual in your health care? Or made a big change in how they got involved in your health care? Describe to me what happened. FOR ADULT CHILDREN: Can you remember when [child] started to get more involved you're your health care? Describe to me what happened.</p>	<ul style="list-style-type: none"> <li>○ <b>What do they do?</b> In what situations?</li> <li>○ Alternate: Has anyone ever had an instance when your family/friends didn't have <b>enough information</b> or the 'right' information about this?</li> <li>○ <b>Would it be helpful if</b> your family or friends talked with you more about what to do when you feel sick?</li> <li>○ <b>What makes it difficult</b> for your family or friends to help you decide what to do when you feel sick?</li> </ul>
<p>In general:</p> <p>[NEW QUEST]: How do you feel about accepting help from your family member/friend? Is it ever difficult?</p> <p>[NEW QUEST]: Does your family member or friend ever do things as part of your health care that you would rather do yourself?</p> <p>Do you and your family member/friend ever disagree about how you should care for your health?</p>	<ul style="list-style-type: none"> <li>○ <b>If yes</b>, how do you handle those situations?</li> <li>○ <b>If not</b>, what do you and your FF do that helps avoid disagreement?</li> </ul>

## Caregiver Interview Guide

Thank you for taking the time to talk with us today. We asked for your input because we are planning new programs that might change the way we support our patients with health conditions that they care for from day-to-day, like diabetes. One of our goals is to better include and support any family or friends who get involved with these veterans' health care. We invited you to tell your story today because you know one of our patients who is managing diabetes, and you have taken an interest in helping that veteran with their health care in the past. Over the next 60 minutes, I'll be asking you several questions. There are no wrong answers. People have different experiences and points of view, and we want to hear them all. We are audio-recording this discussion because we don't want to miss any of your comments. [We also may take some notes so that we can follow up on something you said later on.] We'll use only our first names today, and there will not be any names in our reports. Your comments will be kept confidential [including from your family member]. Your participation is voluntary, and you can ask to skip a question or to stop the interview at any time.

<p>First, I'd like to get some information on your situation, because it helps us understand how you are able to be involved with [veteran].</p> <p>Do you live with [veteran]? If not, how far do you live from [veteran]?</p> <p>Can you tell me who [else] you live with?</p> <p>Do you work outside the home? Full time or part time? what shift? What type of job?</p> <p>Do you have any background or training in health care?</p> <p>Next, we are interested to hear how you try to help the veteran in certain ways, whether or not you feel it is going well.</p>	<p><i>Themes to follow-up on if they come up:</i></p> <ul style="list-style-type: none"> <li>▪ <i>Family/friends who <b>don't live with patient</b></i></li> <li>▪ <i><b>More than one family member involved</b></i></li> </ul>
<p>Do you ever come into the exam room for the veteran's visits with their doctor or nurse?</p> <ol style="list-style-type: none"> <li>1. Think back to the last time you went into the room for the veteran's appointment. Describe what happened at the visit (probe for FF involvement).</li> <li>2. Do you ever encourage the veteran to say more during appointments?</li> <li>3. Which appointments are you more likely to come to? Which do you usually skip? Why do you come to X type of appointment more often than Y?</li> </ol>	<ul style="list-style-type: none"> <li>○ What <b>do you do</b> to try to help the veteran in this situation?</li> <li>○ What is your <b>experience</b> like....?</li> <li>○ If you don't come into the exam room, <b>have you ever thought about doing it</b>?</li> <li>○ Do you wish that you came into the exam room <b>more</b>? Why/why not?</li> <li>○ What would make it more comfortable for you to come to the veteran's visits?</li> </ul>
<p>4. If there is a visit that you don't attend, do you ask the veteran afterwards what happened at the visit?</p>	<ul style="list-style-type: none"> <li>○ What kind of information are you hoping to hear?</li> <li>○ Are you confident that you are hearing everything important that happened? Why/why not?</li> <li>○ Are you confident that what you are hearing is accurate (i.e. what the doctor actually said)? Why/why not?</li> </ul>
<p>5. Do you ever help the veteran get ready for doctor visits?</p> <p><i>For example:</i>  <i>Suggest or write down questions for veteran to ask the doctor/nurse</i>  <i>Remind veteran to bring sugar log or other information</i></p>	<ul style="list-style-type: none"> <li>○ What do you feel is important to bring to appointments?</li> <li>○ If you don't help the veteran get ready for doctor visits, <b>why not</b>?</li> <li>○ What makes it <b>difficult</b> for you to help the veteran get ready for doctor visits?</li> </ul>
<p>6. Do you ever talk to the veteran's doctor or nurse on the phone? In what type of situations? What is your experience like?</p>	<ol style="list-style-type: none"> <li>a. If you don't talk to the veteran's doctor or nurse, <b>why not</b>?</li> <li>b. Do you wish that you talked to the veteran's doctor or nurse <b>more</b>? Why/why not?</li> </ol>

<p>7. Think back to the last time you talked to the veteran's doctor or nurse on the phone – please describe what happened.</p> <p>8. Do you ever encourage the veteran to call their doctor or nurse?</p>	
<p>9. Do you ever help the veteran figure out how to use the VA?</p> <p><i>For example:</i>  <i>How to make appointments or use the pharmacy at the VA</i>  <i>Who to call at the VA when you have a question</i>  <i>What VA health programs you could sign up for</i></p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?</p> <p>b. What is your <b>experience</b> like....?</p> <p>c. Do you wish that you were able to help the veteran use the VA <b>more</b>? Why/why not?</p> <p>d. What makes it <b>difficult</b> for you to help the veteran figure out how to use the VA?</p>
<p>10. Do you ever help the veteran keep track of medical information (like test results or reports from doctors)?</p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?</p> <p>b. What is your <b>experience</b> like....?</p> <p>c. If you don't help track medical info, <b>why not</b>?</p> <p>d. Do you wish that you helped track medical info <b>more</b>? Why/why not?</p> <p>e. What makes it <b>difficult</b> for you to help track medical info?</p>
<p>11. Do you ever help the veteran use VA computer programs (like MyHealthVet, telehealth, secure messaging)?</p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?</p> <p>b. What is your <b>experience</b> like....?</p> <p>c. Have you ever felt uncomfortable ....?</p> <p>d. If you don't N, <b>why not</b>?</p> <p>e. Do you ever use the computer to help the veteran with his/her health care in other ways? How?</p> <p>f. Do you wish that N <b>more</b>? Why/why not?</p> <p>g. What makes it <b>difficult</b> for you to do N?</p>
<p>Does the veteran every go to non-VA emergency rooms or hospitals?</p> <p>12. If yes, do you ever help the veteran figure out what to do next after the veteran goes to a non-VA hospital?</p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?</p> <p>b. What is your <b>experience</b> like....?</p> <p>c. Have you ever felt <b>uncomfortable</b> ....?</p> <p>d. If you don't N, <b>why not</b>?</p> <p>e. Do you wish that N <b>more</b>? Why/why not?</p> <p>f. What makes it <b>difficult</b> for you to do N?</p>
<p>13. Do you ever help the veteran manage medicines?</p> <p><i>For example:</i>  <i>Ask if took medicines</i>  <i>Help refill medicines</i>  <i>Help take insulin</i></p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?</p> <p>b. Have you ever felt <b>uncomfortable</b> helping with medications?</p> <p>c. If you don't N, <b>why not</b>?</p>



<p>14. Has there been a time in the past when the veteran’s diabetes medicines changed? <i>Focus especially on starting insulin or changes in insulin.</i> Describe to me what happened (probe for FF involvement).</p>	<p>d. Do you wish that N <b>more</b>? Why/why not?  e. What makes it <b>difficult</b> for you to do help with medications?  f. Think back to a time when you wish you had more or better information about the veterans’ medications – describe to me what happened.</p>
<p>15. Do you ever help the veteran manage sugars?  <u>For example:</u>  <i>Ask what sugar readings are</i>  <i>Help you decide what to do if your sugars are high</i>  <i>Tell you how they think you should change your medicine</i></p> <p>16. Has there been a time in the past when the veteran’s sugars were out of control, and the veteran had to change how they managed diabetes? Describe to me what happened (probe for FF involvement).</p>	<p>a. What <b>do you do</b> to try to help the veteran in this situation?  b. Have you ever felt <b>uncomfortable</b> ....?  c. If you don’t N, <b>why not</b>?  d. Do you wish that N <b>more</b>? Why/why not?  e. What makes it <b>difficult</b> for you to do help with managing sugars?  f. Would it be helpful to be taught how to use a glucometer? How to change insulin in response to sugar readings? If caregiver learned about these things in the past, how did they learn?</p>
<p>17. Do you ever help the veteran decide what to do when the veteran feels sick?  <u>For example:</u>  <i>Help you when your sugars go too low // cold or the flu</i></p> <p>18. Has there been a time when you got much more involved in the veteran’s health care? Or made a big change in how you were involved? Describe to me what happened.</p> <p>19. Are there any reasons that you feel the veteran is less able to care for their health than they did a few years ago? If yes, describe those reasons?</p>	<p>a. What <b>do you do</b> to try to help the veteran when he/she is sick?  b. If you aren’t able to help, <b>why not</b>?  c. Do you wish that you could help <b>more</b>? Why/why not?  d. What makes it <b>difficult</b> for you to help the veteran when he/she is sick?</p>
<p>In general:</p> <ul style="list-style-type: none"> <li>• Are there any ways that you wish you could help that you aren’t right now?</li> <li>• Are there any ways that you help that you feel nervous about?</li> <li>• What (else) stands in your way of getting involved in the veteran’s health care?</li> <li>• Tell us about why you think the veteran <b>accepts your help</b></li> </ul>	<ul style="list-style-type: none"> <li>○ What do you do to encourage the veteran to accept your help?</li> <li>○ How do you help veteran still <b>feel in charge</b> of their health care?</li> <li>○ If yes, how do you handle those situations?</li> </ul> <p>ALT: Describe a time when you were helping the veteran care for his health, and you were not sure that you were <b>doing the ‘right’ thing.</b></p>

- Do you ever disagree with the veteran about how they should care for their health?
- Does trying to help the veteran with their health care ever make you **feel stressed or confused**? Can you give us an example?
- Do you have **the information you need** to help the veteran?

- Have you ever had an instance when you didn't have enough information or the right information about the veteran's health?